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"Roadblocks, Stop Signs": Health Literacy, Education and Communication at a Free Medical Clinic

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ABSTRACT

This qualitative study, which takes place in a free medical clinic for low-income and uninsured patients, addresses the patients' health literacy and access to health information inside and outside of the clinic setting, as well as the strategies clinic providers use to effectively communicate health information. This study is based on participant observation in an urban clinic in the Northeast, interviews of 22 patients and 20 health-care providers, and direct observation of the provider/patient communication in nine instances. In the clinic, the providers serve as educators for vulnerable, stressed patients, who are adult learners. The patients were interviewed in order to understand their health education needs, their comprehension of the health information that they received at the clinic, and their access to health information outside of the clinic. The providers, who were volunteers at the clinic, were interviewed to understand their strategies to effectively communicate with their patients. This study, therefore, provides insights into how adults learn in nonformal educational settings and what strategies appear to be effective to communicate with people who are marginalized and stressed.

“ROADBLOCKS, STOP SIGNS”
HEALTH LITERACY, EDUCATION, AND COMMUNICATION AT A FREE MEDICAL CLINIC

by

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TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1: INTRODUCTION

The hand-printed sign, "The doctor is in," hung in the window. The clinic's patients and volunteer health-care providers entered through a tunnel-like hallway, covered with layers of old beige paint. Patients at the free medical clinic signed in and wrote the reason for their visit. Patty (all names in this study are pseudonyms) wrote "Everything" as the reason for her visit. She had been seen in the emergency rooms of three different hospitals in the past month. Patty was a parolee who had had Medicaid Medicaid (the federal/state health insurance program for the poor and disabled) until she received Social Security widow's benefits after her ex-husband died. The Social Security income made her ineligible for Medicaid benefits. As a result of this loss of medical insurance, she stopped receiving consistent care for her heart disease and other medical conditions. The doctor who examined Patty at the clinic was concerned that Patty might not realize that she could die because of her lack of access to consistent health care. If Patty had realized this, she might have intensified her efforts to obtain treatment.

Another patient, Egbert, stopped in to get his blood pressure checked. He worked part-time and did not have health insurance. He has been coming to the clinic since it opened in 2007 and has taken different combinations of medications to keep his blood pressure under control. He expressed satisfaction with his care and knew the names of the nurses, especially the ones who have worked at the clinic since its doors opened.

Both Patty and Egbert were adult patients who were served by a free medical clinic in an urban area in the Northeast, which served as the setting for this study. The city where the clinic is located had a total population of just over 140,000, including

25,000 adults who were uninsured. The clinic was one of two regularly operating free clinics for the uninsured in the city. In a three-year period, 1,300 patients were seen at the clinic. Many of the patients were employed in jobs that did not provide health insurance coverage and others had lost employment due to workplace injury and other forms of disability (Lane, personal communication, January 12, 2011).

Statement of the Problem

This qualitative study addressed the health literacy, health education, and health communication in a free clinic for low income and uninsured adults. Through observations and interviews the study examined how patients understood the health information they received and the strategies clinic providers used to effectively communicate health information to their patients. The patients were interviewed in order to understand their health education needs, their comprehension of the health information that they received at the clinic, and their access to health information outside of the clinic. The providers, who were volunteers at the clinic, were interviewed to understand their strategies to effectively communicate with their patients.

Health literacy (HL) has various definitions as described in the sections below; at a minimum it includes the ability to access, read, and comprehend health information (U.S. Department of Health and Human Services, 2003). We are all vulnerable when we have to make decisions about topics about which we do not have expertise; for some of us it is buying a home, for others it is auto repair or a health problem. The ability to access, comprehend, and apply health information is critical to achieving and maintaining good health. Because health advice is often disseminated in printed and electronic formats, reading and comprehension are keys to learning about health promotion issues,

diet, drug dosages and side effects, disease symptoms, clinic locations, and informed consent documents. Nutbeam (2008) describes low literacy and low health literacy as risks that reduce the effectiveness of medical care.

Recent analyses of HL have expanded its definition to include the capacity to obtain, process, and understand basic health information in order to make appropriate health decisions. Health literacy was described by the Institute of Medicine (2004) as a function of the communication between health-care providers and patients, which is comprised of social and individual factors and influenced by education, culture, and language. This broader definition came about in recognition of the many types of information that patients are expected to comprehend and follow through on in health-care settings. In addition to reading texts, patients must also be able to fill out forms, use numeracy skills such as calculating correct doses of medicine, understand what health-care providers say, advocate for themselves, remember and report lists of symptoms and questions, and follow the providers' instructions upon leaving the clinic.

Although low HL has been more frequently documented among disadvantaged and impoverished persons (Hawkins, Kantayya, & Sharkey-Asner, 2010), those with advanced education can also experience low HL at certain times and in certain settings (Zarcadoolas, Pleasant, & Greer, 2006). For example, people with above average literacy may become highly stressed immediately after receiving a diagnosis of a catastrophic illness and be less able to process information. People with normally excellent reading skills may be taking prescribed medications or illicit substances that temporarily alter their cognitive ability. Moreover, many adult patients have cognitive challenges due to learning disabilities (Smith & Strick, 2010), head injuries (Madigan, DeLuca, Diamond,

Tramontano, & Averill, 2000), substance abuse (Lundqvist, 2010), mental illness (Spaulding, Reed, Poland, & Storzbach, 1996), or stress (Staal, 2004) that limit their capacity to understand and follow through on what they read and on their conversations with their providers.

In drafting the protocol for this study, I sought the input of the clinic director, whom I will call Dr. Patterson. She believed that many patients at the clinic struggled with literacy, and consequently, health literacy. During the study I realized that while the majority of the patients that I interviewed appeared to have adequate reading comprehension, many other issues impaired the effective flow of information between providers and patients. For example, many of the patients seen at this clinic were severely stressed due to their illnesses and the difficulty of living in poverty, and others had longstanding problems with substance abuse or mental health issues, each of which could impact a person's ability to access or follow through with health information. These and other issues can affect how patients process, comprehend, and act upon medical advice, even among those with adequate literacy skills. The subsequent chapters present the stories of a number of patients interviewed for this study who had completed some post-secondary education, but at times appeared to have difficulty accessing, comprehending, and following through on instructions from health-care providers.

The clinic met the World Health Organization definition of primary health care, which is ambulatory health care delivered in a community setting that includes education to prevent and control health problems, promotion of proper nutrition, immunization against major infectious diseases, prevention and control of disease, appropriate treatment of common diseases and injuries, and provision of essential drugs (Curtis, 2004).

The clinical encounter between provider and patient in primary care can be viewed as a form of adult education. The provider aims to teach the patient about health risks and how the patient can follow through with healthy behavior (Woloshin, Schwartz, & Welch, 2002). Health-care providers, however, often have limited time; in many clinical encounters providers have only 15 minutes to impart health information to their patients (Jotkowitz & Porath, 2007). They may expect patients to interpret and act on health information that is loaded with difficult and technical vocabulary (Kemp, Floyd, McCord-Duncan, & Lang, 2008). Health education and communication could be improved by the provider's ability to speak and write using accessible language that is at the patient's level of understanding (Barrett & Puryear, 2006).

I was drawn to the study of health literacy because I have two decades as a medical technologist in a hospital laboratory and hold a master's degree in adult literacy and learning disabilities. In conducting this study I was struck by the overlap between patient-provider communication and adult education strategies. Health is one of the most important applications of reading and numeracy skills (Rudd, 2007). Literacy instructors serve the same at-risk populations in adult basic education (ABE) programs as are found in clinics like the setting of this study (Witte, 2010). Adult education guidelines for instruction, particularly those for special education (Smith & Strick, 2010) mirror the American Medical Association (AMA) guidelines for effectively communicating with patients, which emphasize direct instruction, repetition, and feedback (Weiss, 2003). I came to see the clinic as a setting for adult education, and I believe that the results of this study may be significant for both clinical providers and for adult educators.

In addition to my formal education in adult literacy and learning disabilities, I was the chair of a county-wide literacy coalition for programs that provided adult education services. A colleague, who was the executive director of a neighborhood adult literacy center, commented that most of the literacy students had difficulty understanding their health issues and dealing with the health-care system. That was the first time I heard about HL, although I didn't have a name for it then. During this time, I met the project director for the city-wide Healthy Start program, Dr. Sandra Lane, who is the chair of this dissertation. We worked with social service agencies to revise written health messages using plain, easier-to-read language. With the project director, the staff members, and several students, I became a coauthor on an article about HL and the prevention of infant mortality (Levandowski et al., 2006).

The family practice where Dr. Patterson worked sent an e-mail to doctoral students attending area colleges and universities, requesting volunteers to develop research projects for publication. I responded to this request by volunteering at the free clinic for three months in the fall of 2007. I met with the volunteer staff at the clinic and at the food pantry adjacent to the clinic. Sometimes I sat in the waiting room or hallway and chatted with the people who stopped in for food or medical care. On one occasion, a local supermarket donated loaves of bread that needed to be individually packaged and I helped with that task. Sometimes I performed clerical duties such as faxing, copying, filing, and creating new blank charts. On one occasion when the clinic was short-staffed, I met with patients and helped them complete the intake forms.

With the input and permission of the clinic director, I developed my study protocol, obtained IRB approval from Syracuse University, and, from August to

December 2009, observed and conducted interviews with patients and health-care providers at the clinic.

Significance of the Study

Patients from low socioeconomic backgrounds are particularly vulnerable with regard to health literacy issues. Health literacy scholarship does not include many patient narratives about challenges and frustrations while receiving medical treatment. Results of on-site interviews contextualized in a clinical medical setting are rarely conducted. A search of PubMed and Medline, two databases administered by the National Library of Medicine, produced two relevant articles (Hawkins & Lindsay, 2006; Martins, 2008). Moreover, most health literacy research is quantitative and provider-oriented. This study provides insights into how adults learn in nonformal educational settings and what strategies appear to be effective for communicating with people who are marginalized and stressed. Identifying barriers to effective communication, and making recommendations to enhance such communication, could potentially result in better health outcomes for patients.

Health insurance reform, known as the Patient Protection and Affordable Care Act of 2010, was enacted during the time of this study. Patient and health-care provider stories at a free clinic may be useful to policymakers to understand the needs of low-income and marginalized patients. If Medicaid enrollment increases as a result of the new law, use of the free clinic may increase because Medicaid coverage does not currently guarantee access to medical care.

Outline of the Following Chapters

In Chapter 2, I discuss the conceptual framework, theories, and literature that apply to this study, including health literacy, health communication, and adult education theory. Chapter 3 explains the research methods and procedures, including participant recruitment, data collection and analysis, and limitations of the study. Chapter 4, the first data chapter, introduces the patients and highlights their health education needs, their comprehension of the health information that they received at the clinic, and their access to health information outside of the clinic. Chapter 5, the second data chapter, introduces the health-care providers and documents their strategies to effectively communicate with their patients. Chapter 6 presents practical and theoretical implications of this study, as well as recommendations and suggestions for future research.

CHAPTER 2: CONCEPTUAL FRAMEWORK/LITERATURE REVIEW

Health Literacy

Definition of Health Literacy

Dr. Barry Weiss has campaigned to add health literacy as a fifth vital sign to the medical assessment (Weiss et al., 2005). In addition to knowing a patient's temperature, respiration rate, blood pressure, and pulse, Weiss argued that health-care providers should get patient feedback on how much they know about their diagnosis and what is expected of them. The U.S. Department of Health and Human Services defined health literacy (HL) as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, p. vi). The Calgary Charter on Health Literacy (2009, p. 1) defined HL as allowing "the public and personnel working in all health-related contexts to find, understand, evaluate, communicate and use information." The World Health Organization (WHO) expanded the definition of HL to "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (WHO, 1998, p. 10). The WHO definition was the only one that mentions social skills and motivation, in addition to ability, as necessary components of HL (Ishikawa & Yano, 2008). HL was described by the Institute of Medicine (2004) as a function of the communication between health-care providers and patients, which is comprised of social and individual factors and influenced by education, culture, and language; this is the definition that guides this study. This definition of HL moved beyond the abilities of patients, to include the language, cultural assumptions, clarity, and communication skills

of health-care providers as a piece of the health literacy construct. Wolf et al. (2009) followed the conceptual framework of the Institute of Medicine (IOM) by suggesting that the definition of HL recognize cognitive and metacognitive abilities that underlie basic reading skills and that result in "health learning" capacity. Such abilities include attention span, information processing speed, short- and long-term memory capabilities, and reasoning.

The History of Health Literacy

In the U.S., the concept of HL originated in the late 1970s when health-care professionals were concerned about patient compliance issues. Around the same time, adult basic education teachers realized that their students' desire to understand health matters could motivate them to learn. HL also emerged when treatment of acute disease waned and when treatment of chronic diseases such as diabetes and hypertension became more prevalent (Pleasant, 2008). Patients were expected to follow long-term self-care procedures and take on more personal responsibility for their care, including changing daily habits, monitoring symptoms, taking medicines, accessing care, and interacting with health-care professionals.

Doak and Doak (1996) conducted workshops for health-care professionals in the 1980s with the understanding that most health education messages were not comprehensible to a majority of patients. They emphasized that health-care providers should indicate what patients need to do, not facts about the disease process. Doak and Doak also published research findings showing that adults read at a level three to five grade lower than their years of schooling completed (1980). The average reading ability

of the one hundred patients tested was at the seventh-grade level. Most written health education materials had a twelfth-grade readability level.

The number of peer-reviewed journal articles on health literacy skyrocketed after results of two national assessments of literacy were published—the National Adult Literacy Survey (NALS) in 1992 and the National Assessment of Adult Literacy (NAAL) in 2003 (Ishikawa & Yano, 2008). Findings from adult literacy surveys caught the attention of health-care providers who were curious about the link between health and literacy. Hundreds of research studies have shown a dramatic gap between the literacy demands of the health-care system and the ability of individual patients to access and comprehend these demands.

Rudd, Anderson, Oppenheimer, and Nath (2007) found that HL research has moved beyond a focus on the individual patient's skills to consideration of HL as a policy issue concerned with the interaction between the demands of the health system and individuals' skills. In reviewing literature through 2005, the authors identified four strands or research themes:

1. Assessment of the readability of print communication and the match between health materials and the skills of intended audiences.

   Most health education materials are written at a 10th-grade or higher reading level (Michielutte, Alciati, & Arculli, 1999)—higher than the reading levels of most adults. Organizations such as the Plain Language Association International (PLAIN) work to substitute everyday words for medical language, to use short sentences and highlight key points (http://www.plainlanguagenetwork.org).

2. Differences between patients with strong reading skills and patients with limited reading skills related to disease and treatment.

   Being unable to understand or access health information may decrease the likelihood of identifying disease symptoms or inhibit preventative behaviors. Patients may not follow physicians' instructions simply because they don't understand, not because they are deliberately noncompliant (Schillinger et al., 2003).

3. Improvement of communication using new technologies and icons.

   The Internet, multimedia computer software, touch-screen interactive technology, video (including podcasts), photonovellas, and pictographs are all being used and evaluated for health communication. Rudd et al. did not think that their full potential has been addressed or studied.

4. Development and evaluation of programs to improve health literacy. In addition to the wealth of scientific studies on aspects of HL, several governmental and policy bodies have produced reports calling attention to the problem of low health literacy. The federal government implemented guidelines for an action plan about HL that highlighted the need to address characteristics of health systems and emphasized the communication skills of providers, institutional protocols, and print materials in common use (U.S. Dept. HHS, 2003). As mentioned above, the Institute of Medicine produced an assessment and overview of the HL field with concrete recommendations for action by governmental and nongovernmental agencies (Institute of Medicine, 2004). The Agency for Healthcare Research and Quality published

a report that reviewed research linking literacy to health outcomes as a foundation for policy decisions (Berkman et al., 2004). The Educational Testing Service (ETS) reviewed issues in the measurement of HL skills and implications for both the education and health fields (Rudd, Kirsch, & Yamamoto, 2004). In the ETS report, Rudd and her colleagues called for a broader scope of inquiry to include studies about health-related activities in the home, workplace, and community. The reports emphasized the need to examine a broad range of literacy skills, including math and oral/aural language skills, and to develop measures that address all of these skills. They stated that information-seeking skills of patients need closer examination, and new information technologies should be studied.

The National Action Plan to Improve Health Literacy was rolled out in May 2010 by the U.S. Department of Health and Human Services (2010) after public and professional input. The plan supported the HL objectives for Healthy People 2010 and 2020. According to that document, building health literacy skills begins early in life and must be reinforced throughout the educational process, which includes lifelong learning about health. Everyone needs to have access to accurate, actionable health information and person-centered health information and services. Adult education programs, as well as social service agencies, libraries, community-based organizations, nonprofits, and patient advocacy groups can participate in a linked, multisector effort to help individuals and communities to build health literacy skills and find health information and services. The National Action plan contained seven goals, each with identified strategies that will enable a variety of professional organizations and fields to improve HL. The plan also

called for more research on effective strategies to address health literacy as well as evaluations of interventions aimed at improving HL, with wide dissemination of these results.

Functional Health Literacy

Reading. Although health literacy encompasses more than reading comprehension, the ability to read and understand printed material is a big part of the concept. Nutbeam (2008) maintained that the corrosive impact of poor literacy on health remains largely hidden, because literacy demands in the context of health care are often more complex than in the context of everyday life. There are two levels of literacy to consider. First, patients may have adequate reading comprehension, but lack specific health information and the medical vocabulary needed for their medical care. For those with undiagnosed chronic illnesses such as hypertension or diabetes, there is the question of whether they understand the connection between the changes in their body and the need to see a health-care provider. Second, as patients with low general literacy seek health care they face printed and often multisyllabic, esoteric words even before they walk through the door of a doctor's office or an emergency room. In this vein, Roter presented HL as a function of literacy skill in relation to literacy demand, which may be much higher in a clinical setting than in many other settings (cited in Institute of Medicine Workshop, 2010). Just finding the clinic or doctor's office is directly related to patients' literacy skills (Villaire & Mayer, 2007). Many patients lack the skills that are necessary for making appointments, completing paperwork, communicating symptoms, comprehending instructions, and reading prescription labels. Patients with low literacy may have difficulty locating providers and services, filling out forms, reporting on their

medical history, understanding medical terms, seeking preventive health care, managing chronic health conditions, complying with instructions, and taking medications (U.S. Dept. of HHS, Health Resources and Services Administration, http://www.hrsa./gov/healthliteracy/default.htm).

Many adults do not recognize their inadequate literacy (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993); or they do know they have a problem with reading, but are ashamed to admit it and go to great lengths to hide it. Health-care providers may be unaware that the patient has low literacy or may not know how to address the issue. The latest National Assessment of Adult Literacy (NAAL) in 2003 included questions about general literacy, as well as three health-care categories: clinical care issues, prevention, and navigation (Kutner, Greenberg, Jin, & Paulsen, 2006). Clinical care questions assessed knowledge about a specific disease or condition, and generally related to the specifics of a patient's treatment, interactions between health-care provider and patient, and diagnosis and treatment of illness. Prevention tasks dealt with understanding health guidelines. These tasks often involved instructions for preventative health measures, warning labels, and guidelines for preventative screening. Navigational questions addressed the bureaucratic demands of the health-care system including the ability to understand the benefits of a health insurance plan and the individual rights and responsibilities of the patient. The questions assessed three types of literacy: text, document, and quantitative. The four levels of literacy include: (a) proficient, being able to perform complex and challenging tasks, (b) intermediate, being able to perform moderately challenging tasks, (c) basic, being able to perform simple everyday tasks, and (d) below basic, not being able to perform basic tasks; only able to do the most simple

and concrete tasks. The numbers for general and health literacy were essentially the same. Of 19,000 adults surveyed, 14 percent were in the below basic group and 22 percent were in the basic group—a total of 36 percent who have problems with reading (Rudd, Kirsch, & Yamamoto, 2004). Only 12 percent had proficient skills. The remaining 88 percent (almost nine out of 10 people) were routinely challenged by the demands of the health-care system.

Although low literacy is higher for people who are elderly, belong to a minority group, are poor, have dropped out of school, or who have recently immigrated, among adults with low literacy, 50 percent are European American, 40 percent are employed, and 25 percent are high school graduates (Rudd, et al., 2004). Among patients with the chronic diseases, a large proportion has been found to lack the capacity to understand instructions on how to manage their illnesses (Villaire & Mayer, 2009). Smith (2007) suggested that instead of focusing on how many people are health literate, the question to ask is how to create a health literate society where people can find what they need, understand what they find, and use it to accomplish their goals.

Smith (2001) uniquely described literacy in medical terms: hypoliteracy and hyperliteracy. Most, but not all, clinicians are hyperliterate because of their training and daily practice of advanced literacy skills. Although hyperliteracy is usually considered to be an advantage, it can result in clinicians being unable to communicate effectively with most patients. The hyperliterate are usually successful, lifelong learners. The hypoliterate may have had negative learning experiences associated with failure and embarrassment, and approach learning with apprehension.

With technological advances, the traditional definition of literacy has changed to include new subcategories. Norman and Skinner (2006) proposed the new category of eHealth Literacy that includes the interaction of traditional literacy (reading, writing, and numeracy), computer literacy (information technology skills), media literacy (media analysis skills), health literacy (health knowledge comprehension), information literacy (information seeking and understanding), and science literacy (understanding of scientific processes and outcomes).

Two measures of health literacy have been available to health-care providers and researchers: the Rapid Estimate of Adult Literacy in Medicine (REALM, Davis et al., 1993) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995). Although the tests measure basic print literacy, they do not take into account the full set of skills and knowledge associated with HL (Institute of Medicine, 2004). Reading ability, oral and written language skills, lack of background knowledge, lack of familiarity with medical terminology, and cultural differences all affect patient communication.

In addition to the burden of testing, the process of screening for HL may cause feelings of shame in patients. Farrell, Chandran, and Gramling (2008) evaluated HL screening questions developed by Chew, Bradley, and Boyko (2004) that were used instead of a more formal test. The four questions were (a) How often do you have someone help you read medical materials? (b) How confident are you in filling out medical forms by yourself? (c) How often do you have problems learning about your medical condition because of difficulty understanding written information? (d) How often do you need to have someone help you when you read instructions, pamphlets, or other

written materials from your doctor or pharmacy? The four questions were generally acceptable to the study's eleven participants for use as a screening instrument. In addition, most participants believed that it is the patient's responsibility to initiate a discussion about HL.

King and Taylor (2010) studied fourteen adult literacy students who had chronic illnesses such as asthma, diabetes, high blood pressure, arthritis, or other physical problems that had lasted for at least six months. The participants in the study did not find printed health education materials to be useful and did not keep pamphlets or brochures to use as reference material. The printed materials used vocabulary that the students did not understand.

Clinicians often hand a brochure, pamphlet, or fact sheet to patients to supplement their oral teaching. Brochures and posters also line the walls in waiting rooms and exam rooms. The average reading level of a sample of health education material is at a 10th- to 12th-grade level, too difficult for almost half of adult readers in the U.S. (Doak, Doak, & Root, 1996). Readability of written materials has been addressed at length in the literature. Most readability scores state how many years of education are required to read a text. With the exception of a few reading formulas, like the Flesch Reading Ease, which scores passages using percentages, most scores are based on a grade level. The higher the percentage using Flesch Reading Ease, the easier the text is to understand. Grade levels are calculated by using a mathematical formula to produce a numerical score. A score of fourth grade assumes that a fourth grader would be able to read the text. The score does not indicate whether an adult with a specific level of education will be able to read the words. Putting information into a very easy-to-read format at a fairly low grade level is

not only important for people with low literacy, but also for people who are experiencing stress. Furthermore, a lower reading level is only part of the issue. A secondary issue is the use of clear and specific directions to ensure that readers get the intended message (Levandowski et al., 2006).

Software that evaluates readability is often less accurate than counting words, syllables, and sentence length by hand. Periods at the end of acronyms and semicolons can be counted as the ends of a sentence when they are not, resulting in a false number of shorter sentences. A document needs to be cleaned before being evaluated; bullets, URLs, phone numbers, titles, and subheadings must be ignored. Moreover, readability software does not evaluate the quality of the content and the appropriateness of the words.

Readability formulas that are used to evaluate print should not be used exclusively to rate the difficulty of reading print. They should only be used as a "ballpark" estimate. Only two factors, long sentences and difficult vocabulary, are assessed by readability formulas. Other factors to consider include the use of active voice and the use of plain language (as opposed to medical terminology). Beyond readability, suitability factors come into play—whether the text stimulates reading. The content and purpose of a text, its cultural appropriateness, layout, choice of fonts, writing style, and appeal all contribute to whether a medical brochure is read or discarded. The Suitability Assessment of Materials (SAM) is a checklist that addresses all these issues (see Appendix B from Doak, Doak, & Root, 1996).

Newer terminology for readability is "usability" or ease of use (Health Literacy Innovations, http://www.healthliteracyinnovations.com) and "cognitive fluency" or how

easy it is to think about something (Bennett, 2010). Universal design of media allows for accessibility for everyone, including people with disabilities and low literacy. The National Action Plan for Health Literacy described above (U.S. Dept. of HHS, 2010) promoted the use of universal design when creating media about health education. Cultural relevancy is yet another aspect of printed information to consider. For example, stroke caused by hypertension is common in African-Americans, yet the majority of patient instructions may feature European American faces.

Wilson and Wolf (2009) do not believe that improved readability is likely to solve patients' comprehension problems. They used a "cognitive factors" perspective and discussed working memory as being a "mental scratchpad" that patients use to focus on particular, prioritized elements of what they are reading or hearing. Design elements of health materials should minimize the demands on working memory and allow comprehension of the core message. Referring to Mayer's multimedia learning theory, the authors discussed the multiple, distinct stores of working memory; they reported that visual and aural information are processed separately. According to the modality principle, video's dynamic images and audio narration may be preferable to print if it allows patients to encounter information that is less taxing on cognitive processes such as working memory. Video may lessen the working memory load required to comprehend text and, instead, use working memory resources to process relevant information. Print materials have the advantage of allowing for repeated at-home review. The repetition and rehearsal of information support the development of a desired behavior.

Listening. Health literacy advocates have called for research regarding spoken language skills and listening comprehension related to patient-provider communication,

especially with patients who have low literacy. Little is known about individuals' ability to understand spoken instructions. Sticht (1972) tested young men in the military and found that men with lower reading levels were more likely to prefer learning by listening. In a later study, Sticht and James (1984) found that adults did not demonstrate a higher listening ability compared to reading ability, even with adults reading at a second-grade level. White (2009) found an opposite effect when adult students with a second-grade reading level listened to a tape of the GED. The students' skill level sometimes jumped to a 10th-grade level or more. However, not everyone can get meaning from listening to text read out loud, partly because background knowledge and vocabulary may also need improvement.

There is no established test that measures comprehension of spoken health-related information (Baker, 2006). Rosenfeld et al. (2011) assessed patients with asthma using the Woodcock-Johnson Tests of Achievement section called "understanding directions," which simulated listening comprehension, and recall and enactment activities. Participants were given an illustrated drawing and were asked to follow prerecorded directions to point to objects in the picture. A statistically significant association between patients with lower aural literacy skills and less successful asthma management was found. Roter (2011) suggested three strategies to promote dialogue and assist patients to become participants in their own health care:

1. "Strip it down" limits use of complex language and medical jargon.
2. "Bring it home" places information in a personally relevant context, grounding it in the experience of the patient-learner.

3. "Mix it up" avoids mini-lectures and monologues and promotes two-way dialogue and conversation.

Numeracy. High rates of medication-related errors are often due to poor communication and are related to patients' numeracy abilities (American Medical Association Foundation, 2007). Many patients have difficulty understanding common prescription labels and dosing instructions and cannot correctly demonstrate how to take their pills (Davis et al., 2006). If patients are told to take a pill three times a day, they may think they can take one pill when they get up, one after breakfast and the third before lunch. Children with ear infections have had their liquid antibiotic put in their ears in error, instead of correctly taking it by mouth.

Golbeck, Ahlers-Schmidt, Paschal, and Dismuke (2005) proposed a definition of health numeracy in order to distinguish the concept from health literacy: "Health numeracy is the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions." Numeracy is related to health literacy, but makes an independent contribution to patient comprehension and choices (Hibbard, Peters, Dixon, & Tusler, 2007). Reading comprehension and numeracy skills do not necessarily correlate when patients try to understand health information (Golbeck, Paschal, Jones, & Hsiao, 2010). The authors found that 20 percent of patients with low literacy (sample size of 144) had significantly higher numeracy than reading comprehension scores, while an additional 20 percent scored significantly lower in numeracy than in reading comprehension.

Apter et al. (2008) described five hierarchical mathematical concepts related to patient treatment: counting, arithmetic operations, estimating, percentages, and understanding probability and risk assessment. They suggested that health disparities are driven, in part, by poor mathematical ability. Low numeracy/quantitative skills can also undermine a patient's ability to understand health risks and benefits (Roter, 2005). Patients with lower numeracy tend to overestimate their risk of getting a cancer diagnosis, may overestimate the benefits of treatment, and are less able to use risk reduction information (such as scheduling a mammography or colonoscopy) to adjust their risk estimates (Reyna, Nelson, Han, & Dieckmann, 2009).

Behavioral outcomes. Low health literacy is a major cause of economic inefficiency in the U.S. health-care system (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). Poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race (Ad Hoc Committee on Health Literacy, American Medical Association, 1999). A recent national conference about HL, "What's New in Health Literacy Research: A Workshop," was sponsored by the Institute of Medicine in Washington, DC, in May 2010 (IOM, 2010). Dean Schillinger, a physician who is a prominent health literacy advocate, discussed mechanisms that link HL and health outcomes:

1. health awareness—early recognition of symptoms/need for care
2. accessing and navigating complex health and social service systems
3. adherence to taking medications
4. learning and performing self-management behaviors

5. communication in the clinical encounter—medical reconciliation, giving a history, reporting symptoms, understanding explanations and results, asking questions
6. ethical processes—shared decision making, articulating preferences, providing informed consent

Schillinger believes that a socioecological approach will improve individual health and lead to "healthier choices" by vulnerable populations who face food insecurity, food access problems, and unsafe neighborhoods that are part of the social context. He considered the nature of the health systems that care for vulnerable populations: the organization and workplace characteristics of clinics reflect the social capital (the connections and values) of the populations they serve. Schillinger also reviewed studies of HL and diabetes/hypertension that revealed differences by setting. HL predicted disease control in less resourced settings, but not in more resourced settings.

At the same conference, Joshua Seidman emphasized the importance of the four E's: engage, educate, empower, and enable. The meaningful use of health information technology results in better health, transformed care delivery, and a reduction in health disparities. David Baker proposed new underlying assumptions about HL: that poor health outcomes for people with low HL are not simply due to an inability to comprehend print, multimedia, and oral messages. The causes are multifactorial, including differences in background knowledge, community beliefs and norms, information-seeking behaviors, self-efficacy, and health-seeking behaviors.

Nutbeam (2008) maintained that the corrosive impact of poor literacy on health remains largely hidden and views HL as one of the multiple functional literacies (computer, financial, science) that includes an array of cognitive and noncognitive skills to be applied in real life. HL uses information and services to enhance health and is complementary to the prevailing clinical approaches. Both are needed to achieve a health literate society. Citizens/patients use information to improve health behaviors, participate in health care, and exert control over their health, while health systems and health-care providers disseminate quality information and provide support in developing health-promoting practices.

Hibbard, Mahoney, Stockard, and Tusler (2005) studied patient activation as an additional contributor to health outcomes. Patient activation refers to the ability to manage one's own health and health-care and includes four stages:

1. Patients do not believe that they play an active and important role in their health.
2. Patients lack the confidence and knowledge to take action.
3. Patients begin to take action.
4. Patients maintain behaviors over time.

Hibbard developed the Patient Activation Measure (PAM), a 22-item measure that assesses patient knowledge, skill, and confidence and predicts healthy behaviors, disease-specific self-management behaviors, and consumer behaviors. Health literacy relates more to choices and the use of information, while activation relates more to health behaviors.

Hibbard, Peters, Dixon, and Tusler (2007) found that activation may help to compensate for lower literacy skills by increasing comprehension. The Center for Studying Health System Change released information on patient activation based on a nationally representative telephone survey of 17,800 U.S. adults in 2007. "Activation levels are especially low for people with low income, less education, Medicaid enrollees, and people with poor self-reported health (Hibbard & Cunningham, 2008, p. 1)."

Seubert (2009) has broadened his approach to health literacy to include patient activation with the goal of the Six Aims of safe, effective, patient-centered, timely, efficient, and equitable health care.

Health Communication

Health communication is the study and use of communication strategies to inform and influence individual and community decisions that affect health, linking the fields of health and communication. It is a necessary element of efforts to improve personal and public health, and health literacy is a vital piece of health communication. Traditional communication methods are based on the assumption that patients are actively and rationally processing information and will fully integrate that information in future decisions (Bone, France, & Aikin, 2009). One factor that detracts from this idealized state is the time limitations for patient-provider communication (Jotkowitz & Porath, 2007). As a result of time constraints, greater technical and self-management demands are being placed on patients. Patients misunderstand or fail to accurately recall half of medical information given to them (Kemp, Floyd, McCord-Duncan, & Lang, 2008). Providers need to consider the HL status of their patients and provide information in a way that

patients can understand. Patients need support to improve their ability to acquire and understand medical information and to negotiate the health-care system.

Communication during a medical visit is a complex process involving vocabulary, tone of voice, body language, and the interaction style of both the provider and the patient (Williams & Ogden, 2004). Communication is a key component of medical treatment. High stress and emotional levels exert a profound influence on patient cognition and behavior, including information processing, decision-making, and recall.

The U.S. Department of Health and Human Services has developed a patient survey that includes questions about communication. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) asks patients whether providers "listen carefully to you," "explain things in a way you could understand," "show respect for what you had to say," and "spends enough time with" you (http://www.hcahpsonline.org/surveyinstrument.aspx). The survey encourages providers to focus on patient-centered concerns.

As described above, King and Taylor (2010) studied 14 adult literacy students with chronic illnesses. As patients, the participants expected information about their health condition and also expected to be treated with respect by health-care providers. They believed that respect was key to establishing trust and that trust led to effective communication. If there was no respect, there was no relationship between the patient and provider and no effective communication.

Authoritative Knowledge: Whose Knowledge Counts?

Jordan (1997) discussed the theoretical paradigm of "authoritative knowledge" and stated that the power of this knowledge "is not that it is correct but that it counts." (p.

58). It is the information possessed by the elites, which is too often parsimoniously doled out to those in need of the knowledge. It is the basis on which decisions are made and actions taken. Physicians, in this model, are elite knowledge holders who control the discourse and decide what information is relevant. Their communication of this knowledge to patients is less than ideal when laden with impenetrable jargon, and thus can be ineffective when informing patients.

The elitist concept of authoritative knowledge has a long history. The heretic John Wycliffe, for example, challenged the authoritative knowledge of the Roman Catholic Church in medieval times when he translated the Bible from Latin to English. He believed that everyone should have access to the Bible in the language that they could understand, not just obtain their knowledge of the holy writ via the clergy (Hudson & Kenny, 2004).

In the 20th century, the women's and civil rights movements actively challenged medical paternalism. In traditional paternalistic approaches, the doctor had the dominant role and made decisions on behalf of the patient, who was a passive recipient. The 1960s and 1970s were times for protest, dissent, direct action, and antiestablishment sentiment in the U.S. The Boston Women's Health Book Collective challenged the authoritative knowledge of physicians, by translating medical literature into plain language in the publication, *Our Bodies, Ourselves* (1973). Knowledge is power. Informed and empowered women readers took control of and actively participated in their health care, starting a health social movement and a consumer revolution (Keefe, Lane, & Swarts, 2006).

Not all patients want to be part of the decision-making process. Some may just want to be told what is best for them and what to do (Barrett & Puryear, 2006). However, even patients who do not question their physician's recommendations must still be able to understand and perform self-care procedures. Kon (2010) observed that medical decision-making shifted from a paternalistic approach to a patient autonomy standard in the 20th century in the U.S. In the 21st century the standard is shifting yet again to shared decision-making—a meeting in the middle. There is a continuum of shared decision-making because it takes different forms in different situations. Patient preferences must guide what approach is used. The physician should not inappropriately take too much control or force patients to bear more of a burden than they desire. Shared decision-making is part of patient-centered care, and physicians need to present the choices of treatment, explain the pros and cons, and ask the patient about their thoughts on the best choice.

The concept of patient centeredness recognizes and respects the patient's perspective. Optimal communication involves an exchange of ideas, as opposed to being an occasion to transmit technical information from provider to patient (Roter, 2005). Both patient and provider need to share a common vocabulary. Clancy (Institute of Medicine, 2010) believes that in order for patients to become empowered, providers must present patient options in an understandable way. He emphasized that patients should feel that they have a choice, and they must have information about quality and cost.

Reducing HL-related disparities requires significant behavior change on the part of the clinicians who are part of the "culture of medicine," that relies on a distinct language and values efficient transmission of highly technical information. When they

speak with patients, health-care providers may be unaware of how much they use technical language and they may overestimate their patients' understanding of such language. Health-care providers may use unclarified medical language to assert their professionalism or authoritative knowledge, or may try to empower patients by exposing them to such language.

Deuster, Christopher, Donovan, and Farrell (2008) defined jargon as the "specialized language of a trade" or profession, in this case, the language shared by physicians and other health-care providers. Jargon is frequently used and rarely explained by primary care internal medicine residents, suggesting problems with communication and patient comprehension (Deuster, et al., 2008). Castro, Wilson, Wang, and Schillinger (2007) measured the extent of unclarified jargon use by primary care physicians during their encounters with patients with diabetes and limited HL. The investigators conceptualized the problem as a functional mismatch between the skills of the patient and the demands placed on patients by the health-care system and its providers. The authors suggested that increasing clinician self-awareness and reducing "jargon" use could improve the effectiveness of primary care delivery for patients with chronic conditions such as diabetes. Incorporating such strategies could promote more collaborative, patient-centered care. The limiting factor in the physician/patient relationship may be how physicians relay their knowledge to patients to optimize use of resources by patients.

Cultural Aspects of Communication in Health-Care Settings

Lillian Hill (2007b) wrote that people's knowledge and life experience need to be taken into account when they receive medical care. The cultural expectations that the patient brings to the doctor's office is as much a factor in communication as the doctor's

choice of words. A deficiency approach with an emphasis on patient compliance needs to be avoided. The socially vulnerable are also medically vulnerable. Individual factors that affect health-care interactions include patients' health beliefs, their preferences and values, their knowledge and perceptions of symptoms, and their attitudes toward health care (Curtis, 2004).

The National Standards on Culturally and Linguistically Appropriate Services (CLAS) encouraged health-care providers to make their practices more culturally and linguistically accessible. The first of fourteen standards is, "Health-care organizations should assure that patients/consumers receive from all staff members, effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language" (U.S. Dept. of Health and Human Services, The Office of Minority Health, 2001, p. 33). Patients need to know they have the right to receive accessible and appropriate health care. When linguistic and cultural practices of the patient-learner are allowed into the exam room, better learning and communication will take place. Health-related media that are directed toward the general public may not reach the intended, more culturally specific, audience, adding to the disparities in health care (Levandowski et al., 2006).

Communication Strategies of Providers

The Institute of Medicine recommended that professional schools, including medical schools, incorporate health literacy into the curricula and areas of competence. Instruction on clear communication and strategies to ensure patient understanding will enhance students' ability to interact with all patients effectively (Harper, Cook, & Makoul, 2007). The authors described how third-year medical students at the University

of Chicago completed a self-directed online curriculum and also received feedback on how they interact with an actual patient. The final step in the patient visit, closing the encounter, should include summarizing the key components of the visit, involving the patient in health-care decisions, reaching a mutually agreeable plan, discussing next steps, and thanking the patient. After receiving instruction in the teach-back method, there was an increase in the use of teach-back (21% use in 2005 increased to 31% use in 2006). However, since less than one-third of the medical students used the teach-back method after explicit instruction in 2006, more effective curricular initiatives were needed.

The American Medical Association Foundation has published guidelines for clinicians to improve interpersonal communication (Weiss, 2003). The six steps include:

1. Slow down. Speaking slowly does not require much more time and will help foster a patient-centered approach. Behaviors, such as sitting instead of standing, and listening instead of speaking, also give patients the impression that the provider is focused on them. Boudreau, Cassell, and Fuks (2009) pointed out that attentive listening is critical for effective communication, but is often a neglected topic in medical school curricula.
2. Use plain, nonmedical language. For example, say “not cancer” instead of “benign,” “high blood pressure” instead of “hypertension.” There are many other examples of plain language that can be used to promote a dialogue instead of a provider monologue.
3. Show or draw pictures. The most effective pictures are simple ones. Including irrelevant details distracts the patient and diminishes the effectiveness of the

picture as a teaching tool. Houts, Witmer, Egeth, Loscalzo, and Zabora (2001) found that patients with low literacy could recall medical information after four weeks with the help of pictographs.

4. Limit the amount of information and repeat it. Focus on one or two important pieces of information, then review and repeat. Ideally, the information will be repeated by other members of the health-care team.
5. Use the teach-back and show-me techniques. Do not simply ask patients if they understand. Ask them to explain or demonstrate what they need to do. If the patient does not respond correctly, reteach using an alternate approach including audiotapes and computer-assisted education. Schillinger et al. (2003) found that only 20 percent of physicians confirm patient understanding by having patients repeat back instructions.
6. Create a shame-free environment. Be respectful, caring, and sensitive. Patients can be told that many people have difficulty reading and understanding medical information and to feel comfortable about asking questions. Ask patients if they have any concerns that have not been addressed. Encourage patients to ask questions.

Chugh, Williams, Grigsby, and Coleman (2009) described the three components of cognition: working memory, semantic learning (the processing and recall of new information), and executive cognitive function. The authors believed that the teach-back method only assesses working memory and, therefore, may be ineffective with patients who have cognitive impairment. Such patients may be able to restate and demonstrate instructions for self-care, but may not be able to remember at a later time, or they may

remember but fail to perform the task. The authors recommended that both patients and their caregivers receive verbal and written instructions.

Sand-Jecklin, Murray, Summers, and Watson (2010) noted that many health-care professionals are unaware that patients may have literacy limitations, and these professionals often do not know how to intervene appropriately with such patients. Health care providers are often advised to improve their communication by finding out about problems that patients with low literacy have with filling out intake forms, and with reading prescription labels and health education materials (Parikh, Parker, Nurss, Baker, & Williams, 1996). Health-care providers need to be sensitive to the shame and embarrassment that patients with low literacy may experience.

Formal programs encouraging patients to participate during medical visits have been developed, including Speak Up and Ask Me 3. In 2002, the Joint Commission launched a national campaign to urge patients to become active, involved, and informed. There are brochures and posters available on 11 patient safety topics including error prevention, avoiding mistakes taking medicine, and questions to ask health-care providers (http://jointcommission.org/GeneralPublic/Speak+Up/about_speakup.htm).

Ask Me 3 is an education program provided by the Partnership for Clear Health Communication at the National Patient Safety Foundation. Patients are urged to ask three questions every time they talk with a doctor, nurse or pharmacist: What is my main problem? What do I need to do? Why is it important for me to do this? One of the downloadable forms has a checklist, space to write down information, and a card with the three questions, which seem to be easy to read (http://www.npsf.org/askme3/pdfs/Askme_brochure_2_pg.pdf).

Adult Education and Health

Nutbeam (2008) described health literacy from two conceptual viewpoints: clinical risk and personal asset. It is becoming increasing clear that learners with low literacy also struggle with a high incidence of health problems (Levy, 2008). The "risk" viewpoint has emanated from the United States and emphasizes individual literacy capacities such as taking prescribed medicines, making health-related decisions, and being able to self-manage disease. Low literacy is accompanied by poor health-care practices. Since this conceptualization is partly knowledge based, "risk" health literacy can be developed through educational intervention with the patient. Health care providers' sensitivity to patients' literacy level may improve communication and clinical outcomes.

The "asset" perspective is rooted in adult learning concepts and patient empowerment. The World Health Organization (WHO) has adopted a definition of health literacy that reflects this health-promotion orientation:

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health ... Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. (WHO, 1998)

Nutbeam elaborated on this definition, which includes more than a set of functional capabilities. "Asset" health literacy builds upon functional literacy by adding negotiation, advocacy, and self-management skills that allow people to engage in social action for health and exert greater control over daily events. Health-care providers who

use adult education principles invite interaction and participation from their patients, regardless of their literacy level, and draw on patients' personal experiences. Health literacy is the outcome of education and communication rather than being a "risk" factor that may influence the outcome.

Both the "risk" and "asset" concepts of health literacy are dependent on basic literacy and numeracy skills. The "risk" model is more goal-oriented, seeking compliance with treatment. It reflects recognition of the impact of low literacy on the effectiveness of clinical care and helps to minimize the disadvantage of low literacy. The "asset" model can be applied to a broader range of settings, including adult education classrooms and community development programs. Nutbeam allows that the "asset" model is a powerful idea, but practical applications for the social determinants of health have not been developed as yet.

Gillis and Quigley (2004) asserted that adult learning is cyclic. After an event or experience, an adult reflects on the experience and its underlying causes (Why is this happening?) and how the experience fits into a larger picture (What does this mean?). Then the adult identifies what action needs to happen (What do I do about it?), leading to the next experience. The authors used this adult education approach when interviewing low-income adults about their challenges with literacy and health care. King (2004) found that adult learners who had a chronic illness reported that, with increased literacy skills, they also had increased confidence in interacting with health-care providers and filling out health-care forms.

Seubert (2008) reported on a collaboration among a clinic, a technical college, and a literacy provider that resulted in a pilot health-literacy curriculum. Topics included

instruction about what health-care providers do, where to go for health care, how to talk to a health care professional, creating a family health history, and understanding when it is time to see a doctor, as well as health care costs, insurance, medications, and prescriptions. No outcomes of the pilot effort were reported. Lillian Hill has noted on a National Institute for Literacy electronic discussion list (2007a) that funding for adult literacy education is low and that many literacy educators are volunteers who may not be well prepared for their work. Many programs are not learner centered and are organized around normative goals such as functional literacy or earning a General Educational Development (GED) degree. Basic adult education programs (pre-GED and GED preparation) based on the schooling model (Quigley, 2007) are often thought to be stigmatized, second-chance efforts for people who have failed or dropped out of school instead of being an opportunity for lifelong learning.

Adult educators usually aim to experience a sustained educational relationship with students in a relatively friendly classroom environment that supports learning and practicing (Diehl, 2007). The adult education system is a wide-reaching resource that can make a difference in students' lives, especially with curriculum guided by learner input (Quigley, 2007). Health can be a motivational topic for instruction and be supportive of basic skill development at the same time (Greenberg, 2001). Adult educators can reach out to health professionals to share information with students and build their skills. It is possible to develop programs that have outcomes of interest to both educators and health providers (Bennett, Pinder, Szesniak, & Culhane, 2008).

Tate (2009) called for a redesign of traditional adult education based on Microsoft's School of the Future World Summit in December 2008:

Education will no longer operate within the constraints of time and space. Instead, education will be integrated into daily life and some of daily life will count as education. Education will not be about textbooks, curriculum, or classes leading to a degree. Each student will have a customized educational program using open source materials.

The central role of the book will give way to interactive technologies with rich multimedia input. Tate envisioned the transition of adult basic education to a new model in which adults would have the use of authentic materials in a universally designed classroom. Context-based instruction would result in immediately applicable lessons, promoting lifelong learning in a social literacy context.

Advances in technology now include free text-to-speech tools that provide accommodations for people with low literacy, including Microsoft Reader, Natural Reader, WordTalk, AccessApps, and DSpeech. Text-to-speech software can read computer screens and web pages, as well as hard copy text. One of the most recent innovations is reading software developed by Kurzweil that works on a Nokia phone, enabling people to access text everywhere. It is no longer necessary to sit at a computer and listen to text being read; the phone takes a picture of the text and converts it to speech. VALUE, a national adult learner leadership organization, advocated for a shift to "virtual literacy" to help adults with low literacy to independently access and process information in English (VALUE, 2009). Learning the traditional literacy of reading and writing takes time. Virtual literacy eliminates the coding step, making content immediately available.

Health-Care Providers as Educators

Health education that takes place during clinical encounters with patients can be viewed as a form of adult education. Several factors make this educational experience more difficult than it would be in a traditional setting. Patient-provider interactions and discussions may take place intermittently, sometimes only once a year, and the time allotted for an appointment may be just fifteen minutes. Time constraints imposed by health insurance reimbursement schedules force health-care providers to spend less time educating patients. Most insurance plans reimburse services based on procedures and diagnoses rather than prevention and positive outcomes (Ferguson & Pawlak, 2011). With a shift from inpatient surgeries to more outpatient surgeries being performed, many patients are being sent home with complicated disease processes; detailed, complex instructions for self-care; and multiple medications. They may not fully understand their condition (Jones, 2007).

Medical schools are mandated to teach and assess communication skills, but instruction about patients' literacy levels and other aspects of comprehension is not often included in the curriculum (Harper, Cook, & Makoul, 2007). Providers generally overestimate the reading ability of their patients and infrequently use recommended educational strategies (Bass, Wilson, Griffith, & Barnett, 2002; Powell & Kripalani, 2005) such as the AMA guidelines described above. In one study, physicians' overestimation of their patients' literacy level was more common for minorities than for European Americans (Kelly & Haidet, 2007). Providers have been found to view the relationship of health literacy and general literacy narrowly, and to focus on the ability to read, understand, and act on health information (Levy et al., 2008). Adult educators define literacy more broadly as "an individual's ability to read, write, and speak, and

compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals and develop one's knowledge and potential" (National Literacy Act, Section 3, 1991). There has been a disconnect between the health-care and adult education systems that is just beginning to be addressed. Adult education efforts may improve health literacy, but accountability for what adult learners do with improved health literacy goes to the health professional.

Health-care providers might improve their educational efforts by incorporating such concepts as adult learning theory (Knowles, 1990). Knowles's major tenets (in italics below) have been adapted by Helen Osbourne (2008) for use with patients and their health care:

1. *Adults are motivated to learn when topics address immediate needs and interests.* Adults are more likely to learn when the subject matter is personally relevant. A person who has had hip surgery wants to learn how to do daily tasks, not learn about anatomy and physiology.
2. *Adults have a life-centered approach to learning.* Information should be practical and address everyday challenges, such as foot care for a diabetic.
3. *Adults build on experience.* Most adults learn best when new information is presented in the context of something they know about. For example, a patient taking a medication for a heart condition is directed to change medications.
4. *Adults are self-directed.* A patient can let the health-care provider know what issues need to be discussed during an office visit.

Health-care providers intentionally provide nonformal education during the medical visit. Nonformal education is similar to formal education in that both are

planned, organized, and intentional, but it differs in that it does not take place in an institutionalized setting. Informal learning occurs after or between contacts with the health-care provider and can be defined as a lifelong process by which every person acquires and accumulates knowledge, skills, attitudes, and insights from daily living. Informal learning in a health-care setting can also be viewed as problem-based learning. The patient needs a clear understanding of the problem, a plan specific to the problem, an ability to discuss the problem with others, and motivation for self-directed learning.

In an example of nonformal health education, Smith (2009) used a reflective educational model to improve functional HL among low-income pregnant women and new parents. The subjects practiced "Think, Link and Respond." Thinking involved observing an event or behavior. The thinking was linked to prior knowledge and experiences, as well as new information. Then a purposeful response was generated about what action to take.

Barriers to Health Literacy in a Free Clinic Setting

Low-income patients who have no health insurance experience significant difficulties in accessing health care. Health literacy skills are crucial to their success.

Poverty

Siegrist (2000) discussed the social causation of health-related inequities. Individuals are exposed in differing degrees to detrimental health risks such as poor housing, pollution, heavy traffic, and the associated risk of accident. Poverty increases these risks and also reduces the opportunity of developing adequate coping mechanisms such as a healthy diet and access to health care. The long-term cumulative effect of negative emotions such as anxiety, fear, anger, and helplessness are psychosocial factors

that add to the stressful condition of being poor. Poverty is a full-time job; a great amount of time and energy is spent ensuring that the basic needs of food, clothing, and shelter are met. Even when there is access to small neighborhood markets, shelves are filled with cigarettes, beer, soda, and junk food. Fresh meat, fruits, and vegetables are rarely to be found in many urban neighborhoods (Lane, 2008).

Lack of Health Insurance/Inadequate Insurance.

The free clinic in this study served low-income patients who may not otherwise receive medical care. These patients at the margins of the health-care system shared many life experiences with adult education learners and special education students. Ferri (2009) found that many special education students are relegated to the margins of the educational system. Medical access and educational opportunity are both associated with class privilege. Adequate medical treatment is often unavailable for those without health insurance (Broyles, Narine, & Brandt, 2002). Choices are also limited for those on the government-subsidized Medicaid and Medicare programs. Ensor and Cooper (2004) described patient (demand-side) and health-care (supply-side) barriers to medical care and stated that demand-side barriers (including the cost of access, lack of information, and cultural barriers) especially impede the poor and other vulnerable groups. Decisions about whether and where to go for medical care start well before such a patient shows up at the clinic doors.

People without health insurance must balance their needs for medical care with housing and food needs. Kushel, Gupta, Gee, and Haas (2006) pointed out the less severe forms and more widespread aspects of homelessness and hunger. Housing instability, for instance, includes any difficulty paying rent or utilities, spending more than 50 percent of

household income on housing, having to move frequently, living in overcrowded conditions, or "doubling up" with friends or relatives. The definition of food insecurity is having limited or uncertain availability of nutritionally adequate and safe foods or the ability to acquire foods in socially acceptable ways. People experiencing food insecurity worry about whether their food will run out or skip meals for lack of money. Even if people have access to health care, they are more likely to delay care and rely more often on emergency room care than routine ambulatory care if they are experiencing housing instability or food insecurity.

The number of uninsured Americans is predicted to increase from 45 million in 2003 to 56 million in 2013 (Gilmer & Kronick, 2005). Uninsured Americans receive poorer health care than those who are insured. The relationship between health insurance coverage and the health care of adults 18 to 64 years old was reviewed by the National Academy of Sciences (Institute of Medicine Committee on the Consequences of Uninsurance, 2002). The report concluded that, in relation to those with health insurance, the uninsured:

1. Are less likely to receive preventative and screening services and continuity of care;
2. Are in poorer health and die prematurely if they have breast, cervical, colorectal, prostate or melanoma cancers;
3. Have worse outcomes if they have diabetes, cardiovascular disease, end-stage renal disease, HIV infection or mental illness;
4. Are more likely to die, receive less service and substandard care, and become injured if they are hospitalized;

5. Experience a greater decrease in general health than insured patients.

Hasnain-Wynia and Wolf (2010) urged researchers in the health disparities field and the health literacy field to merge their interests and develop targeted, yet broadly applicable, interventions to improve health care for marginalized individuals. The authors discussed aspects of HL that included health communication, health-care quality, health-care equity, and patient safety, as well as the related medical aspects of personalized medicine, coordination of care, the medical home concept (American Academy of Family Physicians, 2006), and health information technology.

This chapter outlined the conceptual frameworks of this study, including health literacy and health communication, health education, and barriers to receiving health care. I also described studies in the existing literature about these frameworks which are constantly being revised to optimize patient health outcomes. The next chapter describes methods and procedures used in this study, how participants were selected, and how the data were collected and analyzed.

CHAPTER 3: METHODS AND PROCEDURES

This chapter describes the qualitative research methods and procedures that were used in this study of health literacy, health education, and health communication among low-income patients and their volunteer health-care providers at a free clinic. Qualitative researchers listen to what people have to say, ask questions, observe, or actively participate in various activities and events. They search for understanding as they enter natural environments (Bogdan & Biklen, 2006). The data collection in this study included semistructured, open-ended interviews and participant observation. My goal in this dissertation research was to document the health literacy challenges and communication experiences of patients and health-care providers in the context-specific, real-world setting of a free medical clinic. The research design drew on Rubinstein, Scrimshaw, and Morrissey's (2000) advocacy for policy relevant studies that are multilevel. Therefore, this study included both patient and health-care provider interviews, focusing primarily on the patient interviews. Direct observation of interactions between patients and providers took place after patient interviews on nine occasions. The inclusion of different strategies to collect information on health literacy and health communication (interviews of patients and health-care providers, as well as observation) also served to triangulate the results. As noted by Fetterman (2010), triangulation is a method that compares data across sources and methods, thereby increasing confidence in the interpretation of the information.

I combined an inductive grounded theory approach (e.g., Corbin & Strauss, 2007) with theoretically derived categories to build a model that best fits the experiences of the patients, discovering concepts and themes from the data, not from prior assumptions or

existing theories. Grounded theory is a reiterative process of data analysis in which the researcher moves back and forth between initial findings to further data collection. As described below in the analysis section, I used this back and forth method to refine my understanding of the patients' experiences. Data are not used to prove or disprove an existing theory. There is interplay among the researcher's experience, the data, and the themes. NVivo8, a qualitative data analysis software program, was used to categorize the data. The manufacturer, QRS International, has stated that the software program can be used to develop grounded theory. The goal was to derive meaning from the interviews, to develop a theory about patients' health literacy, and to describe the strategies that clinic providers use to effectively communicate health information.

First Steps and Time Frame

In October 2007, I met with the medical director and nurse manager of the clinic to seek their approval for the study. They suggested that I volunteer at the clinic twice a week for three months prior to data collection in order to understand its operation and to meet the staff and some of the patients. Each time I also visited the food pantry that is located next door on the same floor of the building, speaking with the pantry staff, and on one occasion packaging loaves of bread that had been donated to the pantry. Sometimes I sat in the waiting room or hallway and chatted with the people who stopped in for food or medical care. I performed clerical duties such as faxing, copying, filing, and creating new blank charts. On one occasion when the clinic was short-staffed, I met with patients and helped them complete the intake forms.

After my dissertation proposal and Institutional Review Board (IRB) application were approved, I interviewed participants, and recorded field and participant observations at the clinic from August through December 2009.

Research Design and Methods

My dissertation research was guided by the following questions:

1. What are the patients' perspectives of their health literacy?
2. How do the patients understand the various printed materials and verbal communications from the providers in the context of receiving care at a free clinic?
3. What are the main obstacles to communication from the point of view of both the patients and the health-care providers in the context of a clinical setting?
4. What strategies do health-care providers use to communicate effectively with their patients?
5. How do patients access health information and what resources (face-to-face, print, TV, radio, video, computer) do they use to access that information?

Setting

The clinic's mission is to deliver primary health care to low-income and uninsured persons. However, it provided care to anyone who walked in the door, including people with "higher" incomes or health insurance. It was staffed by volunteer health-care providers and operated on donations of financial assistance, medicines, and medical equipment from the local cathedral, individuals, and community organizations. The clinic was located in the downtown area of a mid-sized city in upstate New York. The city has high levels of poverty (approximately 25%), with an estimated 25,000

people who do not have health insurance. Forty percent of the city's residents are people of color (U.S. Census Bureau, 2008).

The clinic was one of two regularly operating free clinics for the uninsured in the city. It opened its doors in July 2007 after a year of planning by a parishioner committee at the local cathedral. The rector had challenged the committee to think of new ways that the church could serve the poor. The clinic site was across the street from the cathedral in what is called the emergency services building, which already housed a food pantry. Initially, the clinic had one exam room; it has now expanded to three exam rooms plus a room for intake and taking vital signs, and a room for medical records. The waiting area was part of a large dining room that is used to serve breakfast, specifically for men who were homeless, every Wednesday morning. There were two large murals with religious themes were painted on two opposite walls of the dining room.

The clinic started as an adult-only facility that was open two days a week, Tuesday afternoon and Wednesday morning. It expanded to offer a pediatric clinic once a month in the evening. All patient interviews and clinic observations for this study took place at the adult clinic. In a 2009 brochure created and distributed by the clinic, services for adults are described as "identifying/managing chronic disease, providing immediate care, flu clinics, nutrition counseling, referrals with follow-up, social services to get food, housing & work; offering comfort, trust, & compassion."

Dr. Patterson, the clinic's medical director, often said that the clinic is free to patients, but it's not free to operate. The clinic space was donated by the cathedral. All of the staff volunteered their services, and numerous people made small donations to fund the clinic. This study was conducted during the "great recession" of 2009. Although the

clinic did not charge any fee, patients frequently had out-of-pocket costs. If they needed their blood drawn for tests other than a finger stick for glucose or if they needed a urinalysis, they were required to go to a different clinic on the north side of the city to have the testing done. The patients had to pay the fee for the testing and the cost of transportation. If an X-ray was needed, the patients had to go to an outpatient radiology department at a local hospital and pay for the X-ray.

The clinic relied on donations of medications. When patients returned to the clinic for refills, they often did not receive the same medication they had been taking because the original medication was no longer available or was only available in a different strength. If the clinic did not have the medicines in stock that a patient needed, the patients had the choice of going to a pharmacy near a hospital on the north side of the city. The clinic had an account with the pharmacy and medicines dispensed to patients were charged to the clinic. Another option was that the patients paid for the prescription themselves. Drug discount cards were available from the county and several pharmacies advertised that certain generic drugs were available at low or no cost.

In order to provide the clinic with aggregate data about the patients for funding purposes, faculty and students from a local university and a medical school conducted a quantitative analysis of 600 patient charts, out of the approximately 1,300 patients who had been served to date (Lane, personal communication, January 12, 2011). Approximately 30 percent of the patients were European American and another 30 percent were African-American. The remaining 40 percent were Hispanic, Asian, and eastern European immigrants, as well as some refugees from Africa. Most patients were between 30 and 60 years old.

Additional demographics are listed in Table 1 below:

Table 1

Some Demographics of Interviewees

Description	Percentage
Homeless	50%
Employed	60%
Military veterans	7%
History of Incarceration	28%

Hypertension, diabetes, chronic obstructive pulmonary disease, asthma, depression, anxiety, substance abuse withdrawal, tobacco abuse, bronchitis, pharyngitis, sinusitis, wounds, skin infections, gastroenteritis, and headache were the most frequent diagnoses. Approximately 20 percent of the patients were positive for the hepatitis C virus, 41 percent of patients had a diagnosed mental illness, 41 percent smoked tobacco, 11 percent used illicit drugs, 15 percent had diabetes, 41 percent had hypertension, and 27 percent had pulmonary conditions.

Regarding education, 9 percent of the patients had less than a 10th-grade education, 14 percent had more than a 10th-grade education but less than a high school diploma, 40 percent had graduated from high school but had not attended college, and 37 percent had some post-secondary education including college. Thus, a total of 77 percent of the patients had a high school education or higher, which was fairly close to the

proportion in this city in which the clinic was located, where 80 percent of adults had a high school education or higher (U.S. Census, 2008).

Although the clinic was intended for patients who lack health insurance or health care, some patients were covered by Medicaid, Medicare, veteran's benefits, and the like, but had difficulty getting appointments with doctors. Others were eligible for health insurance and were waiting for approval or had had insurance and let it lapse. Most patients under the age of 65 that had insurance had Medicaid coverage, and those who were 65 and older had Medicare. Medicare does not provide prescription drug coverage for patients and, therefore, they often came to the clinic to obtain medications. Some patients with insurance also preferred to use the clinic as their primary health-care provider simply because it was familiar to them. Patients with mental health issues who had Medicaid coverage may have had difficulty keeping appointments and would not be accepted by other clinics and practices. Some patients just needed a physical for work or school and couldn't get one scheduled quickly enough with their regular health care provider. Patients who came to the clinic with prescriptions written by health care providers not associated with the clinic and who were looking to get the prescriptions filled were turned away. The clinic personnel tried to make it clear to the patients that the clinic was not a pharmacy.

The medical director of the clinic, Dr. Patterson, was a family medicine physician who worked full-time at a practice and volunteered to see patients twice a week at the clinic. The practice model at the clinic was an integrated one, with doctors, nurse practitioners, nurses, pharmacists, church staff, and students working together, all of them volunteers. In addition to providing health care, clinic goals included helping to educate

health-care provider students. The clinic was a training and volunteer site for medical students, graduate nursing students, nurse practitioners, and students, like me, interested in working or researching at the clinic.

Research Methods

The study consisted of four components:

1. Twenty-two patient interviews were conducted to understand the perspectives of the clinic's patients on health literacy, their ability to access and comprehend health information, and their understanding of their communication with providers.
2. Twenty health-care provider (HCP) interviews included two physicians, nine student nurses, one nurse practitioner, four medical students, and four volunteer staff nurses. Among the students interviewed were first- and third-year medical students and nine student nurses who were registered nurses and working on completing their bachelor's degree requirements at a Jesuit college. Interviews were conducted to get the providers' perspectives on HL, to understand how they communicated with their patients, and to document any difficulties they encountered.
3. Nine direct observations of patient-provider communication during the clinic appointment were conducted. This direct observation of patient-provider verbal and nonverbal interactions occurred after the patient was interviewed, and it gave me insight into their communication. It also triangulated (provided an additional source of information) the verbal report I received about their communication.

4. Field notes about the clinic's operations, the interactions of staff and patients, and other observations and thoughts of the researcher were recorded each day.

In addition to the three components above, I conducted a small assessment of the types of health materials distributed by the clinic, and patient preferences for the types of health education materials (print and video) they would like to receive in the clinic. This assessment is found in Appendix B.

Selecting Participants

The research subjects were patients and health-care providers at the clinic. Patients who were 18 years of age and older were asked if they would like to participate in the research study. The selection criteria placed no upper age limit, and included all gender, race, socioeconomic status, religious, or any other identities. A table detailing the demographics of the patients is presented in Chapter 4. Health-care providers that volunteered at the clinic were also asked if they would like to participate in the study. The health-care providers included both professional and student physicians, professional and student nurses, and nurse practitioners. All received an explanation about the study, and all of them signed and received a copy of the written consent form.

Method of Conducting Interviews

The interviews with patients and health-care providers were semistructured and open-ended. Patient and provider interviews were conducted as participants became available. The interview guides are found in Appendix A. The questions were not formally revised during the study, but as I reviewed the initial interviews I probed more deeply in subsequent interviews on topics that the patients mentioned as particularly important. Some of these issues became the themes for analysis, as described in the data

analysis section below. Similarly, as I came to appreciate some of the recurrent themes in the patient interviews, I focused my observations on those issues. One of the themes that patients focused on, which I subsequently probed for and observed more intently, was the issue of filling in forms, as described in Chapter 4. All interviewees received a $10 gift certificate to purchase food at a local deli.

Each interviewee was asked to describe examples of successful and unsuccessful health-care communication. Patient interviews also covered information on demographic variables, educational history, comfort with reading, types of materials that the patient read on a regular basis, health-seeking behaviors, and level of access to technology. An additional issue addressed in the patient interviews was their comprehension and assessment of the written materials given to them by their health-care provider. In addition to the general interview topics, I probed by asking patients to speak more about issues that they brought up relative to communications. There were general topics I wanted to discuss, but I let the participants determine how much to contribute and comment. Among the 22 patients interviewed were five who returned for a follow-up visit. In those five cases I was able to conduct a second interview with the patients. These interviews also became a part of my study.

All observations were documented in my field notes. The interviews were recorded with the consent of the participants and I transcribed them into Word 2007 documents. As described below in the analysis section, the interviews were analyzed using NVivo8, computer-assisted qualitative data analysis software. I took notes to document informal conversations and thoughts about the clinic, and I took field notes about my experiences. After multiple readings of the interviews, I created a coding

schema (the “tree nodes” of the NVivo8 software). The coding schema changed somewhat during the multiple readings to finally include the broad topics of health literacy, health communication, and barriers to accessing health information.

I usually sat at a table that was separate from, but near, the patient waiting area, until staff referred patients to me. When patients were referred to me, I spoke to them about the study and asked if they would participate. On some occasions, I asked patients directly if they would like to participate. A total of 26 patients were referred to me or were approached by me. I interviewed 22 of them. Two patients simply declined to participate. Two other patients seemed either unwilling to answer questions or provide informed consent and were not interviewed. One man in his 60s stated that he would become too emotionally distressed when talking about his circumstances. He was recently divorced and was currently homeless after selling his house. He had been reluctant to come to the clinic, but did sign in after a worker at the Salvation Army urged him to get his blood pressure checked. A second gentleman appeared to be actively hallucinating and seemed unable to provide informed consent for the interview.

During each of the interviews I sought to have as much privacy as possible, given the clinic layout. Some interviews were conducted in one of the three exam rooms, but most took place in a large common room that also served as a waiting area and dining room. I was able to sit at the far end of the room so that the interview conversations would not be heard by others. All patients chose to and were able to answer all of the questions I posed. Three patient interviews that were included in the data ended abruptly when patients were called to go to an exam room. The three patients then left the clinic shortly after being seen by the doctor. I stopped interviewing patients and providers when

it seemed that I was getting some redundancy or data saturation in the stories I was hearing. The interviews were relatively brief. Most were 15 to 20 minutes long. Four were one-half hour or longer. There are 365 double-spaced pages of transcribed interviews.

I asked the 20 volunteer health-care provider and student interviewees about their job descriptions, training, and experience in patient communications, as well as examples of patient nonadherence and suggestions for improving communications. As described fully in Chapter 5, I analyzed the provider interviews with a specific focus on their understanding of health literacy, the strategies they used to effectively communicate with their patients, and any challenges they had experienced in health communication. The interviews were 15 to 20 minutes long, except for the interview with the nurse practitioner, which was an hour long. There are 163 double-spaced pages of transcribed provider interviews.

Direct Observations

Direct observation of patient-provider communication was possible with nine of the patients after they were interviewed. Observations were conducted during clinical encounters, with the approval of the patient and the health-care provider. At the time of obtaining the written informed consent, patients were asked if the researcher could observe the end of their health-care visit when a health-care provider spoke with them. The researcher did not observe any physical exam or other time when the patient was not fully clothed. The observations took place at the end of the patient's visit when a health-care provider was advising patients about what to do about their health issues. These direct observations of patient-provider communication allowed me to compare the

interviews with the direct observation of the communication. This use of multiple methods to address the communication of health information was useful for triangulation, the use of multiple sources of data to provide multiple perspectives on a research question (Richards, 2005)

Data Analysis

The transcribed interviews were coded and analyzed using NVivo8, a computer-assisted qualitative data analysis software. Tree nodes are used to represent categories in a hierarchical structure, moving from a general category to more specific categories for classifying behaviors, ideas, and events. I used the "back and forth" pattern of the grounded theory methods from the initial interviews, to subsequent interviews and observations, to progressively focus more on themes that emerged from the patients' narratives and the observations of their communication with the providers. This comparative method produced successively more abstract categorizations of the data. I generated codes, which were then grouped into concepts of significant importance; where there were underlying uniformities in codes, I formed them into a higher-level category. Thus, codes form basic categories of information, categories are selected for a theoretical model (axial coding), and a story is created from the interaction of the categories (selective coding). Categories about the patients in this study included falling "in between the cracks," filling out forms, emotional state, and "I've got to take care of myself." The goal for this study was generating a local theory, rather than a formal theory.

Emic" and "Etic"

The qualitative analysis that I used also draws on social science's division of concepts into two categories: "emic," from the word "phonemic," and "etic," from the

word “phonetic.” These two terms were first used by the linguist Kenneth Pike (1967), who realized they could be used to describe any human social behavior, not just linguistic behavior. Anthropologists have adapted this distinction in their categorization of ethnomedical data (Warren, 1975), which makes the terms particularly useful in this study of patients in a free clinic. An “emic” account describes behavior in terms that are meaningful to the actor (in this study, the patients and providers). An “etic” account uses terms more meaningful to the observer/researcher, often drawn from published literature on the topic, in order to make more universal comparisons or take a world view (Harris, 2001; Schensul, LeCompte, Nastasi, & Borgatti, 1999).

The questions that I constructed for both patients and staff, and for the analysis of their responses, were designed to capture both the emic and etic perspectives. Open-ended questions were used to elicit patient stories about their experiences with the health-care system. The patients were prompted to describe their feelings about their successes and challenges in making sense of health information and getting their health needs met. For example, some patients felt that they were “falling between the cracks” and others mentioned the overwhelming frustration in filling out forms to access services.

Based on the literature review in Chapter 2, the conceptual frameworks of health literacy and communication form the etic variables for analysis. The etic variables, therefore, reflect the concerns and language of researchers and major health-care organizations, such as the Institute of Medicine (IOM) and the Agency for Healthcare Research and Quality (AHRQ). The codes drawn from this etic perspective include such categories as literacy, reading comprehension, and cognitive difficulties.

Table 2 below presents the variables that I used in my analysis of the interviews and observations. In the table, I separate the variables according to whether they emerged from an analysis of the data (emic) or they were derived from previous literature on the topic (etic). I also separated variables that were related to the patients' experiences from the variables related to the providers' experiences.

Table 2

Variables Used in Analysis of Interviews and Observations

Themes	**Patient Emic**	**Patient Etic**	**Provider Emic**	**Provider Etic**
Fiscal challenges		**X**		
Health insurance		**X**		
In between the cracks	**X**			
Reading ability/Literacy		**X**		
Filling out forms	**X**			
Numeracy		**X**		
Money	**X**			
Listening		**X**		
Emotional state		**X**		
Mental illness		**X**		
Stress	**X**			
Self-esteem	**X**			
Taking care of myself	**X**			
Self-efficacy		**X**		
Health literacy				**X**
Health communication				**X**
Confidence			**X**	
Real world vs. ideal			**X**	
Medical jargon			**X**	
Challenges at the clinic			**X**	

Study Limitations

Patients and health-care providers were recruited from a single downtown site, which limited the scope of the study geographically. Results and conclusions may not apply to other clinics, especially if the clinic charges a fee. A limited number of patients were interviewed and their experiences may not be representative of all patients at the clinic. As described above, I decided not to interview two patients—one who described himself as stressed and anxious and a second patient who appeared to be actively hallucinating. Not including these patients might appear to limit the study by excluding patients with psychiatric symptoms. This potential limitation is somewhat counteracted by the inclusion of three patients with severe psychiatric diagnoses who were interviewed, along with four with less severe diagnoses of depression and/or anxiety.

Ethical Concerns

Regarding recruitment and informed consent**,** I fully explained the study to potential participants. If they agreed to participate, written informed consent was obtained. The consent form was read to the patients before they were asked to sign it. It was not assumed that the patients would be able to read the consent form which was approximately at a ninth grade reading level. Three patients seemed to be somewhat offended that I was reading the consent form to them and said that they were able to read the form on their own. In these three cases, I stopped reading the form out loud and the patients silently read the form and then signed it. The consent form included a statement that the patient's medical care would not be affected.

Regarding psychological/emotional discomfort**,** patients and health-care providers may have been uncomfortable discussing events and may have been concerned about

confidentiality. The informed consent documents included a statement that participants could chose not to answer a question, and they could stop the interview and withdraw from the study at any time. Three participants appeared to be uncomfortable during a request for an interview, and I tried to clarify how they felt. One of the participants remained uncomfortable as indicated by verbal and nonverbal actions, and the request for an interview was rescinded.

The informed consent document clearly stated that participation in the study was entirely voluntary and followed the Health Insurance Portability and Accountability Act (HIPPA) standards (P.L. 104-191, 1996). Informed consent documents are required to include extensive detail on how the participants' health information will be kept private. No research records associate the interviewees' name with their responses. Participants are identified using a first name that is an alias. One patient was concerned about confidentiality and was reluctant to have the interview recorded. After assuring him of anonymity and that only the researcher and her advisor would hear the recording or read the transcript, he agreed to sign the consent form. At the end of the interview, he did not voice any further concerns about confidentiality.

Although the patients may not have benefitted personally from their participation, they may nevertheless have derived some satisfaction from telling their stories. They may have learned more about their health condition after talking with the researcher. Their satisfaction as consumers of health services may have increased. These patients may show increased compliance with medical recommendations, resulting in fewer emergency room visits and decreased health-care costs. Health-care providers may make changes in how they communicate with their patients, particularly after discussing the American

Medical Association's communication guidelines. Assessment of such outcomes was not included in this study.

CHAPTER 4: PATIENTS' HEALTH NARRATIVES

"This is a really good place. It's a Godsend."
—Gail, a patient with a mental health diagnosis

This chapter addresses health literacy and health communication from the point of view of the patients in the free medical clinic. As a physician and anthropologist, Kleinman (1988) asked patients to describe their experiences with illness. He found that patients' lives are shaped by psychological and social aspects of chronic medical illness and that patients' narratives help explain how life problems are created, controlled, and made meaningful. I adapted Kleinman's illness narrative concept as a way to understand the patients' health literacy experiences as described in their own words.

The first sections in this chapter describe the patients' demographics, health insurance coverage or lack thereof, economic struggles, employment, and education. The next sections address the patients' health literacy, using the broad definition of health literacy from the Institute of Medicine (2004), which encompasses health communication, listening, processing of information, and the ability and motivation of patients to access and follow through in applying health information in their lives. Additional issues emerged from the analysis of the interviews and observation that were pertinent to health literacy, including whether or not the patient had a mental health diagnosis, fell "in between the cracks," or encountered "roadblocks" in filling out forms. The narratives offered by the patients also illustrate the difficulty of being poor and trying to navigate a complex health-care system.

An important aspect of accessing health information has to do with authoritative knowledge (described in Chapter 2), a theoretical concept that addresses two intertwined issues. As outlined by Keefe, Lane, and Swarts (2006), who applied the concept of

authoritative knowledge to health concerns, the first issue is the access that patients have to health information, both inside and outside of clinical settings. The second issue is whose opinion is trusted or whose knowledge "counts." Historically, health-care providers' use of medical information, dispensed to patients as jargon, had the effect of obscuring communication (Deuster, et al., 2008). As described in Chapter 5, contemporary clinicians often make an effort to speak and communicate more clearly. Moreover, contemporary society is awash in health information, from print, radio, television, video, and Internet sources. However, poverty, low literacy, and cognitive difficulties bar access to some of this information, as described in this chapter.

Patient Demographics

Table 3 below provides demographic information about the patient interviewees at the clinic.

Table 3 Demographic Information About Interviewees at the Clinic

Patient Name	Race	Gender	Age	Education	Medicare	Medicaid	Previous Incarceration	Homeless	Stated Reason for Visit	Work
Linda	AA	F	20's	HS		Yes		Yes	Physical(MH)	
Meg	AA	F	20's	GED		Pending			Physical (for school)	
Bill	EA	M	50's	Some college		Yes		Yes/RM	Physical (for housing)	
Sherman	AA	M	50's	Some college		Pending		Yes	Physical (for job), Asthma	PT
Daryl	EA	M	60's	Not a HS grad			Yes		Depression	Retired
Richard	EA	M	40's	GED		Yes	Yes	Yes YMCA	Asthma	1.
Patty	EA	F	60's	HS		Yes	Yes		"Everything" CHF,Db,MH COPD	
Chuck	AA	M	40's	HS			Yes	Yes/RM	HTN	Looking
Dave	EA	M	40's	GED		Yes	Yes		Db, MH, Asthma	Volunteer
Trevor	AA	M	50's	Bachelor's degree		Pending	Yes	Yes/RM	HTN	Looking
José	Latino	M	50's	Master's degree					Db	
Ethan	EA	M	60's	Bachelor's degree		Yes		Yes	Db, MH	
Robert	AA	M	50's	Some college		Yes			HTN	
Gail	EA	F	40's	Some college		Yes	Yes		MH	
Larry	EA	M	50's	Some college		Pending		Yes YMCA	HTN	
Egbert	AA	M	60's	HS					HTN	PT
Nick	EA	M	50's	HS		Yes			Cirrhosis Hepatitis C	
Brian	AA	M	60's	HS	Yes				Db	Retired
Sara	EA	F	50's	HS					Db, MH	
Kathy	AA	F	50's	HS					HTN	PT
Cedrick	AA	M	50's	Not a HS Grad	Yes				HTN	
Lisa	AA	F	40's	Not a HS Grad					HTN	

Note. AA = African-American; EA = European American, RM = Rescue Mission, CHF = congestive heart failure, Db = Diabetes, HTN = hypertension, COPD = Chronic Obstructive Pulmonary Disease, MH = Mental Health, PT = part-time.

The demographics of the study participants closely reflect the overall adult patient clinic population, as described in Chapter 3. The patients whom I interviewed included 11 African-Americans, 10 European Americans, and 1 Latino. An unexpected finding was the relatively high number of European American patients, since African-Americans in the city experience poverty at approximately twice the rate of European Americans. (U.S. Census, 2008). Although the city has substantial racial segregation, the equal proportions of the two races seen at the clinic may be due to the clinic's downtown location, which is somewhat distant from neighborhoods where the majority of African-Americans reside. The breakdown of the patient interviewees by gender was 7 females and 15 males. This finding was consistent with the clinic's overall demographics and is due in part to the clinic's outreach to men living at the Rescue Mission, the YMCA, and another local homeless shelter. Two African-American females were in their 20s. The remainder of the patients were in their 40s or older.

The stated reason that most patients gave for coming to the clinic was to receive treatment for a chronic disease, such as diabetes, hypertension, or asthma, or a mental health condition. Seven (about one-third) of the patients interviewed reported that they had a mental health condition. As described in the methods section, I recorded their stated reasons for coming to the clinic during the interviews and did not review the patients' charts. Four patients who were interviewed came to the clinic for physicals: two needed a physical for school (the two African-American females in their 20s), one for employment and the fourth as a requirement for subsidized housing. Paying for a pre-employment physical is often beyond the reach of those who are unemployed and uninsured. Two patients who came to the clinic for physicals had Medicaid coverage. Linda made a spur-

of-the-moment decision to come to the clinic to find out what the clinic offered. She reported having been diagnosed with a mental health problem and was a patient at a nearby community health center. Bill lived at the Rescue Mission and was referred to the clinic by the Rescue Mission to expedite getting a physical required for subsidized housing, since no appointment is necessary at the free clinic and an appointment with a physician who accepted his Medicaid insurance might have taken considerable time.

Fiscal Challenges

Most study participants were struggling economically. None of the 22 patient interviewees was employed full-time. The patients who were most financially secure included Daryl, who had retirement income from a pension; Egbert, who worked part-time; and Sara, whose husband had a full-time job. Although these three patients had regular incomes, they could not afford to pay private health insurance premiums. Egbert's employer did not provide medical insurance coverage. Three patients were employed part-time. Besides Egbert, Kathy worked part-time and had dependent children. Sherman also worked part-time as a maintenance worker, but was homeless because he did not have enough money to pay rent.

Economic difficulties led to barriers to health-care access, including transportation barriers; inability to pay for medication, and problems obtaining healthy food. Only Ethan and Sara drove cars to get to the clinic. Everyone else arranged rides with friends or family members, walked, or rode the bus. Daryl lost his license when he was sentenced for a DWI offense. Dave and Sherman both experienced pain when walking. Sherman was homeless and had considerable pain in his hip. A two-day itinerary that he described to me included walking to a community health center, then to

the clinic, then taking a bus to a pharmacy at a local hospital across town, and finally going to the X-ray department at another local hospital.

Eleven of the patient interviewees who needed medications and did not have Medicaid or other insurance for medications were often unable to pay for their medications. The clinic staff tried to meet this need by stocking medications donated by pharmaceutical companies and also funding an account at a local pharmacy for medications that were not otherwise available. These patients also sought assistance through a variety of charitable pharmaceutical programs. Sara received diabetic medications at no cost from a pharmaceutical company that ships the medications directly to the clinic. She also compared drug prices at different pharmacies and had two discount prescription cards for drugs that the clinic does not provide. Cedrick stated that the Salvation Army provided monetary assistance for prescriptions. He hadn't received assistance himself, but knew of others who were helped. He said, "You take the prescription to them and they'll help you pay for it. They'll direct you to go somewhere else where you can get it filled."

The clinic providers recognized that when they advised patients with chronic diseases to eat fruits and vegetables or low-fat dairy products, the patients had great difficulty in following through with those recommendations. Most of the study participants lived in neighborhoods that lack large grocery stores selling such food (Lane, 2008), and their limited budgets do not always allow for the purchase of healthier, but more expensive, food. I observed that many of the clinic patients used the food pantry next to the clinic, where the donated food consists mostly of canned items, cereal, and day-old baked goods. The patient interviewees described how difficult it was for them to

follow the dietary recommendations. Lisa used food stamps and noted that Mrs. Dash, a salt substitute, is expensive. Sometimes, a patient had to choose whether to spend money on health care or food, as in the case of Ethan, who said:

> They did take my blood for diabetes and I paid them cash, I believe, to draw the blood. It wasn't a payment to draw the blood. It was a payment for the lab to check the blood … So it was cash right on the line. It wasn't much, but it was enough for me to not have food that day.

Health Insurance

From the interviews, it is apparent that the patients who are uninsured, unemployed, or both, struggle with getting consistent and adequate health care. The cost of health care is prohibitively high for them, with the result that they often have to choose between health care, food, or shelter. The patients' narratives show that they have adopted strategies for using the few health-care options available to them.

Half of the study participants had no health insurance. Of these 11 patients, four had applied for Medicaid (the federal/state health insurance program for the poor and disabled) and were unsure if their pending requests would be approved. Lisa was denied Medicaid coverage for complicated family reasons. Two of her adult sons with developmental disabilities lived with her and received Supplemental Security Income (SSI) and Medicaid benefits. Lisa stated that in order to receive Medicaid, her benefits would have to be linked with her sons' cases. She was unwilling to do go along with that.

Nine patients had Medicaid coverage. According to Dr. Patterson, one of the reasons that patients with Medicaid come to the clinic is that they have difficulty accessing health care elsewhere, in part because most private practices do not accept patients with Medicaid. Patients reported to me and Dr. Patterson that they experienced long wait times for appointments at hospital clinics and community health centers that

have no restrictions on the number of Medicaid patients. Some patients with Medicaid coverage also report that they prefer to be seen regularly at the free clinic because they have established relationships with the health-care providers.

This was the case for Gail who takes three medications for her mental health condition. Dr. Patterson, the clinic medical director, commented that some patients, such as Gail, may not be accepted as patients at a private practice because they have difficulty going to scheduled clinic appointments on the right day and time, following through on referrals, refilling their medications on time, and the like. Gail had worked as an operating room technician in the past and was familiar with medical jargon, but she was often unable to show up for appointments even if she had the best intentions. A walk-in clinic served most of her needs.

Sometimes Medicaid-covered patients are seen just one time at the clinic, which they use as a kind of urgent care or walk-in facility. Richard had a primary care physician, but Medicaid would not pay to replace his lost inhaler asthma medication, which he needed that day. Nick needed his medications because his Medicaid coverage had lapsed for one month. Linda and Meg came to the clinic for physicals for school and did not anticipate returning to the clinic as patients.

Brian and Cedrick had coverage from Medicare, the federal health insurance program for people aged 65 and older, but lacked prescription coverage for their medications, which they could not afford. Therefore, Brian came to the clinic to get insulin, syringes, and needles for his diabetes. Cedrick had been a patient at the clinic since it opened in 2007 in order to get the medications he needed to control his hypertension.

Four patient interviewees who were in their late 50s or early 60s had recently lost their jobs. From their interviews, it appeared that those four patients were less able than they had been in the past to physically do the jobs they once did. For example, Nick had worked as a carpenter for 40 years and had recently had surgery performed on both of his wrists. He also had hepatitis C, cirrhosis of the liver, and lymphoma that was in remission. If such patients do not qualify for Medicaid, they face being uninsured until they become eligible for Medicare at age 65. Ethan commented:

> So my quest is to find affordable medical insurance or run the risk of hospitalization and medications as an uninsured for three more years (until he is 65) through the clinic ... My long-range thing is to turn a corner and try to work toward my wellness and try to figure out how to manage within the system since it seems to be slanted against a 62 year old. There's very expensive private insurance which I cannot afford ... But for the person who really wants to recover, there's all these roadblocks, stop signs, issues. It makes it challenging to overcome these. It takes a person who is willing to fight to do it. Otherwise, the urge is to give up and become another ward of the state.

Many "roadblocks" are described in this study. Five study participants spoke of using the emergency room (ER) as their health-care provider because they did not have insurance. The last time Meg went to the ER she had shortness of breath, which was the reason for her visit. She attributed the shortness of breath to her smoking and being overweight. After going to two different ERs within one month, she was diagnosed with acid reflux. Richard used the ER when his asthma became acute. Linda and Robert also mentioned going to the ER because they had no other alternatives for health care. Robert said it was a "constant battle trying to get any medical help." When Trevor was asked if he had any advice for others, he replied:

> I think a lot of people shrink away from health care. It's how people were brought up. I think that it's a lack of trust, as well as the financial factor. And a lot of people don't have benefits. So a lot of people won't go down and engage themselves in the public assistance. So I think my advice is to be patient and

> utilize the different processes that are available to help you deal with your medical issues whether it's going through public assistance, whether it's coming to the free medical clinic.

Incarceration

People released from prison switch from having all of their basic needs taken care of on the "inside" to fending for themselves on the "outside." Although I did not ask about it in the interviews, seven study participants volunteered the information that they had been in prison or were currently on parole. This issue is relevant to health literacy because when inmates are released from correctional facilities they often have chronic health conditions and no health insurance. They may not know where to obtain health care. According to Dr. Patterson, a man with insulin-dependent diabetes was released from prison with sufficient insulin for one week and without any way to obtain any more. Fortunately, he was directed to the clinic, where he continues to receive care for his diabetes.

Falling "In Between the Cracks"

Many of the patient interviewees described situations in which they were awaiting decisions on eligibility or were ineligible for services. And for some, as described above, they were waiting until they reached the age of eligibility for Medicare. These "pending" states affect the daily lives of the study participants, and especially affect how they access health care. In contrast to Ethan's "roadblocks," Sara described such situations as being "in between the cracks." The following section describes two patients who not only exemplify being "in between the cracks," but also illustrate the hard work and strategizing of those without insurance to get needed health resources.

Patty, a 61-year-old European American female, wrote, “Everything” as the reason for her visit when she signed in for the first time at the clinic. She had heart disease, depression, and emphysema, and was very overweight. She was on oxygen and pulled a portable tank with wheels behind her. She had had Medicaid until she turned 60, but lost her Medicaid eligibility when she began to receive Social Security widow’s benefits after her ex-husband died. She was incarcerated at a state prison at the time and was therefore unable to reapply for Medicaid or to contest her loss of benefits. She applied for Social Security Disability (SSD), but was denied because she hadn’t worked long enough to qualify. Patty was hospitalized three times in August 2009 at three different hospitals for her heart disease. She was admitted after going to the ER by ambulance each time. Dr. Patterson used the similar phrase of “falling through the cracks” when describing Patty’s situation. Dr. Patterson was not sure if Patty understood that she could die, and decided to call Adult Protective Services to determine if anything could be done to get Patty back on Medicaid. I interviewed Patty during her second visit to the clinic. Sandy, from Adult Protective Services (a county agency), was also present, and with Patty’s permission also participated in the interview. Sandy had visited Patty at her apartment and also discussed Patty’s Medicaid case with a worker at the Department of Social Services (DSS). According to Sandy, Patty would have to pay a “spend-down” of $149 per month on her health care from her own money, and Medicaid would pay for any expenses over $149. Patty said she could not afford to pay the spend-down and refused to pay it. She reasoned that if she didn’t see a doctor for a month, she’d still have to pay the spend-down and receive nothing. Her recent hospitalizations cost her over

$30,000, for which she was billed but which she was not able to pay. Hospital collection agencies were regularly contacting Patty for payment.

Patty was a high school graduate and spoke slowly in a monotone voice. She described having taken a computer class while she was in prison and did volunteer work at her attorney's office after her release. Patty was resourceful and had called the county Department of Aging to find out about financial assistance for her medications. She was referred to the Partners of Partnership program, which helped her to get most of her needed medications at no cost. Patty also received food stamps, assistance with heating costs (HEAP), and got transportation to the grocery store from Catholic Charities. She liked the apartment where she was living, but at the request of Sara, she was looking into her options for a cheaper place.

Patty allowed me to observe her interactions with Dr. Patterson during a clinical appointment. The clinic was busy and so Dr. Patterson listened to Patty's heart and lungs through her clothes in the waiting area instead of going into an exam room, possibly, in part, because of her mobility issues. She was given most of the medications she needed, except Plavix, which is expensive and was not available. Dr. Patterson told Patty to continue taking 325 mg of buffered aspirin instead. She had her blood pressure taken and had a fingerstick for glucose (which was normal). Dr. Patterson listened to her chest with a stethoscope and reassured Patty that her lungs sounded better. After Dr. Patterson finished, I reviewed Patty's understanding of what Dr. Patterson had told her about the medications, which was consistent with what Dr. Patterson had told her. Although Patty's health conditions were quite serious, she seemed to be actively strategizing to access resources for health care, medication, housing, heat, and food. She communicated clearly

with Dr. Patterson and understood and was able to recall all of Dr. Patterson's recommendations to her during her clinical visit.

Ethan, a European American male in his early 60s, fell "in between the cracks" due to job loss and divorce. He had worked for 30 years in "corporate America" and reported being "eased out" of his job 13 years ago. He had been covered by his wife's health insurance until 2008 when they divorced. Ethan had an associate's degree in business and a bachelor's degree in administration. He brought his notebook computer with him and used it as an organizer and to record his medical history and bills. He listed his medical conditions as Crohn's disease, diabetes, heart disease, skin irritations, gout, and an anxiety disorder. He described applying for SSD three times and being denied all three times, as he said, "The manifestations of the Crohn's disease and diabetes were enough to say that I was sick, but not sick enough to qualify [for Social Security disability]."

After two hospitalizations for gout in March 2009, a social worker at the hospital suggested that Ethan should call the county Department of Aging. He did call and was then referred to a worker for the Salvation Army, who helped him to fill in the Medicaid forms and to receive temporary Medicaid coverage. For Ethan, as with many other patients at the clinic, the process of filling out forms was onerous. His most recent "roadblock" occurred when he was scheduled for a colonoscopy and refused to sign a form stating that he would be responsible for paying the bill if Medicaid did not pay it. An office staff member determined that Ethan did have Medicaid coverage, but said that he would still have to sign the form. After refusing to sign the form three times, Ethan

left without having the colonoscopy, saying, “I was becoming a pest to everybody now and indicated that I would not sign the form worded that way.”

At the free clinic Dr. Patterson helped Ethan with the forms for SSD and Medicaid, but to qualify for those benefits he would have to give up his home, which he was reluctant to do. Ethan reported that he was struggling to maintain his autonomy, but, despite Ethan’s considerable efforts to manage his illnesses and his finances, the stress of his difficulties appeared to overwhelm him. During our interview, Ethan showed me his briefcase, which was filled with a clutter of papers. He also wrote down everything that we discussed in the interview and seemed flustered when he couldn’t find some insurance information he needed on his notebook computer. He also had written down some questions he wanted to ask the doctor, but couldn’t find the paper when he was in the exam room.

Education/Reading Ability

Education level and reading ability are not the sum total of health literacy, but are certainly a central part of it. As described in Chapter 2, the literacy demands for health literacy can be higher than the demands for other settings and are exacerbated by the stress of the medical environment, resulting in lower patient comprehension of health issues. Of the 22 study participants, 3 had not finished high school, 3 others had a GED, and 16 had received a high school diploma. Of the 16 high school graduates, 5 had some college, 2 had four-year degrees, and one had a master’s degree in bilingual education. In writing the proposal for this study, I sought the input of Dr. Patterson and other providers at the clinic, all of whom believed that low literacy was a critical issue among the patients.

As described in Chapter 2, the literature on health literacy and reading comprehension indicated that almost half of the general population had low health literacy (Rudd, Kirsch, & Yamamoto, 2004). The interviews and observations with my specific subjects on the issue of literacy and health literacy, however, did not entirely agree with the literature.

An important caveat in interpreting what I found is that I did not formally test the literacy levels of the patients. Dr. Patterson and other clinic providers thought that formal literacy testing might be too difficult to accomplish, potentially interrupting the flow of patients in the often-crowded clinic. Therefore, I indirectly observed the study participants' literacy abilities as they read and filled in the required intake forms for the clinic. I also asked them during the interview about their comfort with reading, what types of materials they read on a regular basis, their use of computers, and how they accessed health information.

Most of the 22 study participants easily read the required intake forms at their first visit to the clinic and the informed consent for this dissertation research. Eleven patient interviewees described themselves as being good readers. Only three, or possibly four, patients showed indications of having low literacy. As mentioned in Chapter 2, adults read three to five grade levels lower than their years of schooling completed, and the average reading ability of a group of 100 patients was found to be at the seventh-grade level (Doak & Doak, 1980). In this study, since 19 patient interviewees had completed high school or acquired a GED and 8 of the 19 had attended college, a fair estimate would be that they had at least an eighth-grade level reading ability. However, having adequate general literacy does not necessarily mean that a patient will also have adequate

health literacy, because stress, illness, and high readability levels of printed health information can negatively affect health literacy.

Because providers at the free clinic had a limited amount of time to interact with patients, and because a considerable amount of home care may be required of the patient, providers often handed a brochure, pamphlet, or fact sheet to patients to supplement their oral teaching. Brochures and posters also lined the walls in waiting rooms and exam rooms. With regard to the use of the printed brochures, Nadia, the certified diabetes nurse educator at the clinic, said, "I think we, as professionals, tend to hand out lots of literature. We don't really spend time explaining what that literature means." Sherman offered a patient's point-of-view: "I would read them [printed handouts] myself, if I was interested in them ... Like this pamphlet, right now, osteoporosis, I'll be reading that."

Unfortunately, printed materials given out in clinical settings are often at an inappropriately high reading level or contain messages that vary substantially from one another, thus confusing the reader (Levandowski et al., 2006). A small study on the appropriateness of the printed materials offered to patients by the clinic, which I conducted to assist the clinic, also found that the brochures were written above the reading level of many clinic patients and used confusing language (see Appendix B).

Some patient interviewees routinely read printed materials. Three mentioned reading books to get health information. As described below, Robert read his father's medical textbooks. In the past, Kathy and her sister had looked for health information in "quality books." Interestingly, Bill believed that novels written by Robin Cook provided reliable medical information. Dave and Sherman mentioned reading the local newspaper. In the past, Larry relied more on reading, but now prefers to watch DVDs. José and

Sherman mentioned that they would read pamphlets or information sheets given to them at the clinic. Four patients, Lisa, Cedrick, Brian, and Nick, did not mention reading as a current activity and gave no other indications that they relied on print materials for information.

Many of the study participants had had their health conditions for some time. Most had not actively sought out health information about their medical conditions because they had high levels of experiential knowledge. Richard was familiar with all the terms about asthma because he'd had asthma since childhood. Larry said, "I'm knowledgeable about blood pressure and all that because I've had high blood pressure all my life." José had family members with diabetes and was familiar with the disease before he learned he was a diabetic, saying, "I know the symptoms. I know the routine."

Eight of the study participants had completed at least some college. For example, Trevor had a bachelor's degree in social sciences, would like to get a master's in theology, and considered himself to be a good reader. Some who had attended college appeared to be active readers and sought out information from print. For example, Sherman was a college student for one year and stated he was "OK with reading" and selectively reads sections of the paper.

> You know, I'll get a newspaper and read the sports section. Or sometimes on occasion, I might read the local (news), what's going on in the local. But I'm not on the front page and stuff like that … If it was something I was interested in, like this pamphlet right now, osteoporosis, I'll be reading that.

Robert probably had the highest reading level of all the patients and was on a temporary medical leave from a business school. He described himself as a "nerd" and said that his father was a pediatrician. He reported reading his father's medical books to learn about his medications and health issues.

> [My Dad has] a lot of medical books. I'm very well read. So if I had something that I was not aware of or needed to be aware of in terms of medication and my health, I usually turn to those medical books. They helped me a great deal.

At least three of the patient interviewees appeared to be good readers when they were asked to sign the informed consent for this dissertation research. Gail had majored in telecommunications at a community college in the past and she expressed frustration when I read her the informed consent. She was one of three who commented that they were able to read the informed consent and that it wasn't necessary to read the form to them. It appeared that Gail's reaction was an example of how shameful the issue of low literacy can be. Perhaps that shame was compounded by the fact that most of the patients were able to access health care only at the clinic.

Not all of the study participants who attended college expressed similar comfort with reading, however. For example, Larry, who attended college for two years on a football scholarship reported, "I barely made my grades. I was no brain. . . .With all those DVDs, I don't read no more. You buy a DVD now. It's like a book." Larry said that reading can be a challenge sometimes. He was referring to his recent experience of applying for Medicaid, which might be a challenge for anyone.

> Reading, you know ... Sometimes it feels like it's going swish in the brain. Like with some of the stuff I got from Medicaid, all the instructions ... "What do they mean by this?" I'm going to bring all of that stuff to her (the Medicaid worker) tomorrow. I'm going to have her explain what it means.

Among the eleven patient interviewees who were high school graduates or who had a GED, there appeared also to be a range of reading ability that was observed by me or reported by the interviewees. An example of someone comfortable seeking out printed health information included Kathy. If she or her sister wanted to learn more about a topic, she said, "We would look it up in books that we had, books left over from school."

Kathy would also "go on computer or find quality books to look at." Similarly, Meg, who had earned a GED, thought that she was a good reader. When asked what she liked to do for fun, she said, "Reading. I like to read books, mysteries and urban novels."

Richard and Dave, both high school graduates, expressed some lack of reading confidence. Richard said, "I'm not a great reader. I'm not a bad reader. Like I said, I used to read books when I was in jail. So I've read a lot of books, if that's what you want to know." Dave read the local newspaper and sports magazines, but when he had to read and fill out medical forms, he said, "It's tough because sometimes I don't understand the big words."

Brian had graduated from high school and reported that that he read well enough to get by, but he had problems with his eyesight because of his diabetes. Brian appeared to have low literacy, but this may have been due to his vision problems. Brian had been a maintenance worker and retired at age 60. He was uninsured because he had not understood how to continue the health insurance from the school district where he worked, information that was included in the retirement documents that he signed. As he described, "I was supposed to get in touch with the school board and let them know that I still wanted to purchase the insurance."

The three study participants who didn't finish high school all reported some difficulty with reading. Daryl struggled with spelling and had tried to improve his reading simply by trying to read more often. I observed him reading a book in the waiting room. Cedrick went as far as sixth grade and liked math, but did not think that he was a good reader. When Cedrick signed the consent form, he did so very slowly and laboriously. Lisa had completed 11th grade and when asked if she did much reading, she said, "A

little bit. I can read, but the bigger words are a little difficult. Some I don't understand. And I ask someone, 'Can you help me out with this word?'"

An unresolved issue is whether it is low literacy or low vision that affects patients' ability to read print. Regular visits to an ophthalmologist to test vision, and medication or surgery to deal with such visual problems as glaucoma or cataracts, were beyond the means of most of those without health insurance. Even new glasses, for those without financial means, may not be available. Lisa appeared to have low literacy when she signed her last name incorrectly on the consent form, but she was not wearing her glasses because they were broken.

Filling out Forms

Although low literacy did not seem to be an issue with most of the patients interviewed, the majority of them reported difficulty in completing paperwork required by social service agencies. The volume of forms, difficulty of language and vocabulary, and uncertainty about what is specifically being asked could be unsettling. The consequences of improperly filling out forms could mean that people are denied services for which they eligible or they may even be suspected of fraud. The experiences of Ethan and Nick illustrated the stress, anxiety, and confusion that many of the patients experienced in filling out the forms.

Ethan, who was described earlier in the section about falling in between the cracks, also had great difficulty filling out the forms. After two hospitalizations for gout in March 2009, Ethan explained that he applied for Medicaid with the help of a worker from the Salvation Army. Ethan submitted all the required forms and received coverage in July 2009. The Medicaid coverage only lasted until his 62nd birthday in August 2009,

with the possibility of coverage being extended through September. For Ethan, as for many other patients at the clinic, the process of filling out forms was daunting. Ethan explained:

> The forms were unbelievably long. One form was 26 pages. It included a brief rundown of all my medical history and symptoms and the systems in my body. I had to list all my doctors. All my medical records were faxed over to the (county DSS office). And only then would they do a review. At the same time, I filed with the federal people for Social Security Disability.

Nick was challenged by the length of the forms required by the IRS to dispute a levy. Nick received $912 a month as a Social Security benefit, and the IRS automatically deducted $155 from this amount as a levy against Nick's 2004 tax return. Medicaid based Nick's income on the gross amount, even though he received $155 less. Nick described his interactions with the IRS:

> I'm more patient because I've got a caseworker this time who knows it better than me. I'm telling you. I've got no money. The other day they [the IRS] sent me twenty papers to fill out, no self-addressed stamped envelope. I had to walk it down to the Federal Building. I said, "The next time you send me something, please send me a self-addressed stamped envelope."

I asked, "What did they say?" Nick replied: "They did it. Actually, I was being honest. It wasn't like you could put a regular stamp on it. It weighed too much.

Kathy could have been eligible for Medicaid, but was unsure whether she wanted to apply:

> Well, I don't know. I'm sure I do qualify, but I've been a little hesitant and concerned about applying. I'm a little nervous about applying. To be honest, I'm a little uncomfortable. I'm not really sure what the protocol and procedures are and how that's going to affect me in the long run. I've heard a couple of different stories of how to get it, the amount, all kinds of crazy things.

I interviewed Carol, a nurse at the clinic, and she gave a health-care provider's point-of-view on filling out forms (cited in Palmer, 2009). She described the false

perceptions that the homeless and the unemployed are lazy and that it was easy to apply for government-subsidized health care. Carol mentioned that assessing the various regulations about eligibility for government subsidies (Medicaid, Medicare, and Supplemental Security Income) and filling out the required paperwork is a demanding task for anyone.

Listening

An important aspect of health communication involves a patient's ability to listen to the words of the provider, and also for the provider to listen, in turn, to the patient. Greater attention to aural literacy on the part of both patient and provider can enhance communication and patient health outcomes. Cedrick was the only patient to comment on listening when asked about his learning style, saying, "I like to listen. The more you listen, the better you understand it." His preference for listening may have been due to his self-described low reading ability. Several of the other patient interviewees appeared to have difficulty in attending to the providers. For example, one patient whom I did not interview appeared to be actively hallucinating. The voices or images that he appeared to be attending to made it difficult for him to communicate with me. In other instances it seemed that the patients' anxiety or health problems (for example, dizziness or shortness of breath) made it difficult for them to attend to a conversation with me or their provider.

A nurse practitioner commented about patient listening skills:

> I think it's very difficult for people to hear information about themselves. We had some people (not at the clinic) who were extraordinarily intelligent and well informed, people who were professional health-care providers, physicians, professors ... And at times they had missed certain pieces of information that were really rather important. And I think partly it was information overload. The other piece was ... it's very hard to hear very complex information about your own health care. At a certain point, I don't know, my theory is the protective mechanism in your own brain takes over and you just kind of do a

> whiteout. “I’m not going to just hear this right now. I can’t possibly be that sick.”

Numeracy/Money

As described in Chapter 2, the ability to understand and follow through with numeric concepts is essential for taking the appropriate doses of medications, interpreting a nutritional label, and managing one’s finances. Higher-level analytical numeracy tasks related to health include determining whether glucose or cholesterol blood levels are within a normal range. Statistical health numeracy comes into play when patients consider the relative risks and benefits of their health-care choices (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005).

Four study participants stated that math was their favorite subject in high school. One of the four majored in business management in college. Another patient, Nick, had been a carpenter for 40 years and used his math skills on the job.

Because most of the medications stocked by the clinic were donated, the strength of a specific medication given to patients could vary. Returning patients who needed refills may have had to take a different number of pills, even though the medication and dosage were the same. This was the case with Lisa and Patty and their blood pressure medication. For example, a medication might be available in 5 mg tablets on one occasion and 2.5 mg tablets on a subsequent visit. Patients would then have to double the number of pills they took.

Some of the other patient interviewees described struggles with money management. Sara and her husband had arranged for Sara’s brother to set up a budget and pay their bills because they were unable to successfully do so themselves. Nick couldn’t

afford to pay his Medicaid spend-down one month and incorrectly thought he could pay for his medications himself.

> We never realized how much the prescriptions were going to cost until she (his daughter) called and checked. This is the medicine that I've been taking for a year already. These are new ones. The price of this one is $1,694 and that's for 28 days. And there's four refills. Who's got that kind of money? This other one's for $2,553. I never knew how much medication cost. I thought that I could pay for it out of my pocket. No way.

Patty's reluctance to pay a Medicaid spend-down may have been due to more than her inability to pay. It is possible that her reluctance to pay the $149 monthly spend-down was related to Patty being concerned about having enough money to pay for living expenses. The benefit of having health insurance for her serious health conditions was not a priority for her.

Cognitive Ability and Emotional State

Poor psychological health is a predictor of health-risk behaviors such as smoking, saturated fat consumption, and physical inactivity, which in turn are associated with increased morbidity and mortality in chronic illness (Helitzer et al., 2010). Primary care physicians, not mental health-care providers, bear much of the burden of treating these patients because of the limited availability of mental health care, even if patients have good health insurance. With uninsured patients, Dr. Patterson emphasized the importance of addressing mental health issues, but she was also troubled by the lack of available medications and the lack of continuity of care. She commented about communicating with these patients:

> They have mental health issues, but they're still perceptive and they're still very much in the fullness of your humanity. And no matter how psychotic or crazy… they recognize kindness and they recognize authenticity. They might not trust you fully, the way with someone who isn't psychotic, but they recognize it. And I find that those two things open communication in the most mentally ill, the

> most stressed out people. And there are people who are very anxious or struggle with other aspects of the health-care system. And they could go elsewhere, but they choose to come here.

Literacy demands in the context of health care are often more complex than in the context of everyday life. Even people with proficient academic skills can have difficulty comprehending health information when fear, stress, and worry are added to the mix, especially the stress of being poor. Patients' cognitive ability can be permanently or temporarily compromised by stress, medications, age, and/or mental health status. Seven of the twenty-two patient interviewees had significant mental health issues, including Patty and Ethan, whose case studies were described earlier. Ethan commented:

> The health issues that I had were manifestations, physical manifestations of an emotional and anxiety disorder, namely Crohn's disease, diabetes, heart issues and skin irritations. They're longstanding and I personally believe that they are connected to an underlying anxiety disorder ... When I was in a situation (13 years ago) where I was eased out of my job and took it very personally and was unable to cope with the loss. And struggled for several years with anxiety and a loss of self-esteem. It affected my marriage shortly thereafter, where I was wanting to sell my home and lost my marriage in that we legally separated. The underlying anxiety and depression was such that my spouse was not able to understand why I wasn't able to work. At the same time, my physical ailments became more and more pronounced. I was hospitalized, diagnosed with Crohn's disease, very acute.

Nancy, a volunteer nurse who is also a diabetes educator, responded to Ethan's comment that he's in an "emotional hole." She advised him to seek out people he can talk with about his situation. She also suggested that Ethan write down events that anger him and brainstorm what he can do to avoid focusing on his anger, frustration, and stress.

Study participants coping with stress and symptoms of mental illness reported that they sometimes had difficulties in listening and paying attention to their providers. Others found that the medical information helped to reduce their anxiety. Linda, for example, felt scared before she learned of her mental health diagnosis 10 years ago at the age of 16.

She was relieved that she could take medication to help her symptoms. Subsequently, Linda described herself as being "lazy," although she realized that, in fact, her medications made her actions and thoughts slower. Linda was concerned and somewhat ashamed about being late for appointments. It seemed that her medications may have affected her ability to show up on time. She learned to make medical appointments for later in the day because it's difficult for her to get up and around in the morning.

Chugh et al. (2009) suggested interventions for helping patients with cognitive impairment (problems with memory, language, thinking, and judgment), including asking questions that require only a yes/no response, using gestures, modeling the desired behavior, and reducing environmental distractions. Patients with mental illness report cognitive impairment while taking antipsychotic medications. The drug effects include "reduced or slowed mental processes, mental clouding and feelings of reduced intelligence" (Moncrieff, Cohen, & Mason, 2009, p. 107). Estroff (1981) studied people with schizophrenia and went to the extreme of taking psychiatric medications to get a sense of the side effects, including involuntary movement. Howland (2010) warned of the adverse effects of discontinuing drug therapy and recommended that medications be discontinued gradually to minimize discontinuation effects.

Although an in-depth analysis of the cognitive ability of clinic patients with mental illness was beyond the scope of this study, seven interviewees were taking medications for a mental health diagnosis. Daryl went on disability for depression and currently does not have a driver's license because of a DWI conviction. He frequently attended Alcoholics Anonymous meetings. During visits to the clinic, he received counseling from a social worker. After being released from prison, Dave was a patient at

a psychiatric hospital for 18 months because of depression, anxiety, and a panic disorder. There were a lot of days when Sara didn't want to leave the house because of her depression and worrying about her family's financial circumstances. She did express some optimism about her family's finances and that her daughter's school performance might improve. A nurse practitioner commented:

> The really mentally health challenged people really require quite a bit of time so that you can establish a relationship that they will perceive as being a safe relationship. And sometimes it takes a little bit of time to figure out how you need to modify your line of questioning or behavior, so that there will be confidence to be able to say what they want to ... And sometimes it's a matter of somebody like the doctor (Dr. Patterson), who has got an outstanding relationship and history, where the people come to trust you over a period of time because your behavior is consistent, predictable and they perceive it to be caring in their own best interest, which is an interesting thing for people with some of the very severe mental health issues ...

Four patient interviewees who did not have a mental health diagnosis described how everyday stress affected them. The usual stresses of life can be amplified for those having little money or no health insurance. According to Larry,

> It's the stress. I haven't driven a truck in seven years. I have to go through another training course. I've been out of circulation and I have to go to school again. My mother got sick. That's why I came off the road. I had to take care of her.

Sherman described his fear and anxiety that was caused by his asthma:

> Basically I'm a type of person, to go out to a doctor, I'd have to be just about dying, you know ... It scares me now. My breathing was bad. I'm scared. I always had asthma. So now my breathing, the shortness of breath, this walking is all kicking in together ... I'm very concerned about that and my breathing. I think I'm being closer to being the oldest left, the fourth oldest left and, you know, we just buried my mom in March. And I'm just scared. I'm scared right now.

Sherman did say that he was working on his health issues and "trying to get this together for me."

Trevor's days were filled with making living arrangements and applying for jobs after being released from prison, which caused him enormous stress:

> Some days get long. It's the stress level. It's the self-esteem. It's not just the wait. It's just a whole lot of stuff to go into. The whole public assistance, the DSS, the whole situation. And a lot of people do get discouraged when that's all you got. I've got a bachelor's degree, but I'm not there right now. I just returned back to the community. I'm not going to neglect my health and myself because I can't be patient, because of how I feel about myself.

Stress, emotional difficulties, and mental illness can decrease a person's overall health literacy. Their impact can vary greatly, from internal racing thoughts that make it hard to pay attention, to a decreased ability to process information, to fatigue that makes it hard to enact intended behaviors. Psychotropic medications to treat mental illness and alleviate psychological distress, which several of the patients reported taking, can further reduce health literacy by increasing restlessness (Howland, 2010). In addition, the patients' subjective experiences of taking psychotropic medications can include "sedation, cognitive impairment and emotional flattening or indifference" (Moncrieff, Cohen, and Mason, 2009, p. 102).

"I've Got to Take Care of Myself"

Health behaviors such as improving diet, losing weight, and taking prescribed medicines routinely are often described as being influenced by the patient's level of self-efficacy (Conner & Norman, 2005). Bandura (1977) defined self-efficacy as confidence in one's ability to succeed in specific situations. Many of the study participants proudly spoke about how they were actively trying to improve their health despite poverty, stress, limited access to care, and, for some, difficulty in obtaining health information. Both Linda and Meg, African-American women in their 20s, had recently lost weight. Linda returned to her former exercise regimen that emphasized walking. She also changed her

unhealthy eating habits to healthy ones, eating more vegetables. Instead of frying food, she switched to using the oven, saying, "I'm trying to get people to understand about baking in the oven. Trying to season with different seasonings, to bring out the flavor more ... salt free, you know, not so much salt."

After being diagnosed with gastric reflux, Meg decided to lose weight by walking, drinking more water, and eating "lighter" foods. Although she smoked cigarettes, she decreased her smoking from one pack a day to one cigarette a day. Both women expressed pride about their efforts to become healthier. Ethan, a diabetic, discussed food choices with the clinic's diabetes educator. Ethan said that he used to run marathons and that he knows he has to take "one step at a time" and "is trying to find a way to live with my illnesses and not being able to work."

Two of the patient interviewees with diabetes reported that they had made significant progress in taking better care of their health. Brian, for example, who had had diabetes for a few years and gradually realized he had to stop eating candy and other sweets said:

> If it [his glucose level] goes higher, into the twos or threes [hundreds], go to a doctor or a hospital. You'd better hurry up because it can either take you out or put you into a diabetic coma. That's what I was told. So I've learned a lot now. And I'm going to stick to it.

José, who was also a diabetic, said that he knows he needs to eat smaller portions of carbohydrates, such as rice. He described how he has been more successful with baking or steaming food, instead of frying it.

Some study participants began to adopt healthier behaviors only after significant health problems began. After Nick developed cirrhosis, he stopped drinking beer:

> I never considered myself an alcoholic because I didn't drink every day and I drank beer ... For some reason, [I thought] beer wasn't alcoholic. I just learned so much in the past few years.

Nick became an expert about his health issues after initially being reluctant to ask questions, a positive example of adult education in the medical arena. With increased knowledge, he became more confident and assertive and was able to be an advocate for his medical and nonmedical issues.

For three patient interviewees, confidence in the ability to take care of themselves led them to offer their services without pay. Patty had spent time volunteering at her lawyer's office doing computer work. At the clinic, D collated the forms for patient charts and organized the storeroom. Robert was thinking about volunteering at the clinic until he was well enough to return to school.

Other patients, however, described what they viewed as their failures to follow a healthier regimen. Lisa, for example, tried "to take the stairs a lot of the time, but that don't help." She knew that she should eat more vegetables and "stay off the salt" but found that hard to do. Larry seemed to know the dietary guidelines to follow to lower his blood pressure, but instead mostly ate food that he said was not good for him: "I've had it [hypertension] and I know I should be dead … I smoke and I drink coffee in the morning. I eat sausage, pepperoni." He said he knew that "I've got to take care of myself," but lost his motivation many times. Even though those patients seem to blame themselves, in the inner city location where most of them lived, it was extremely difficult to obtain fresh produce, low-salt prepared food, and low-fat dairy products.

Most of the clinic patients described in this section seemed to be spending considerable time and effort to address their health-care needs. The emotional

commitment was considerable as well, given the financial status of the patients and the demands of the social services agencies.

Accessing Information

Online

In the last decade, the availability of information has skyrocketed because of the Internet (Lupiáñez-Villanueva, 2011). Health-care providers realize that information from the Internet is not always reliable and that it can even be inaccurate and dangerous. Many websites may be less than adequate sources of information because of high word density, use of jargon, or a layout filled with advertisements, companies promoting their services and products, or just plain inaccuracies. Providers can be at a loss when trying to instruct patients about how to evaluate information found online. Although higher-income patients may come to their office visit with computer printouts, this did not seem to be the case at the clinic. Nevertheless, some patients did use the Internet.

Of the 22 patients interviewed, three had the knowledge and ability to search the Internet; and 10 of the 22 had had no computer training or experience and relied on friends or family who were computer literate for computer-generated information. An additional two patients stated that they only played games on the computer. Of the 10 who had more extensive computer knowledge, four had computers in their home and one used a mobile phone for Internet access. Three of the five had current Internet access.

Kathy said that she had had Internet access at home in the past, but could not afford it right now. She did comment that she would go to the library and use a computer there. Linda had lost her library privileges at the county library and, instead, went to a medical school library that offered computer use to the public. Only two of the 10 had

actively searched for health information on the Internet. One of the 10 was prohibited from using a computer as a condition of parole. Eight had the ability, but not the interest, to do a health-related search. The patients were aware of locations where they could get access to computers—the county library, a county employment office, the Rescue Mission, and the medical school library that is accessible to the public.

Traditional Interpersonal Communication

The 22 patients interviewed in this study were asked what they would do if they had any questions about their health after they left the clinic. Their responses were similar to the findings of a Pew study describing how people acquire health information (Fox & Jones, 2009). Many of them said family, friends, or health-care providers would be a source of information if they had questions about their health or treatment. Eight patients replied that they would ask a health-care professional, and nine would ask a friend or family member. Even though a friend or family member may be in the health-care field, usually working as a nurse's aide, they may have no better understanding than the patient about what happened during the clinic visit.

Summary

The gender, age, and race of the patient interviewees closely reflected the demographics of the general patient population at the clinic. Most interviewees had low or no income and, therefore, faced barriers to health-care access, including transportation, high cost of medications, and inaccessibility of healthy food. Eight study participants were homeless or had recently been homeless. Half of the study group had no health insurance, nine had Medicaid coverage, and two had Medicare coverage. The two patients with Medicare coverage lacked drug coverage and came to the clinic to get their

medications. Seven of the patient interviewees volunteered the information that they had been in prison or were on parole. Unexpectedly, low literacy did not seem to be an issue for most of the study participants. Of the 16 high school graduates, five had some college, two had four-year degrees, and one had a master's degree.

Although the majority could read, health literacy was an issue. From the study participants' point of view, some were falling through the cracks, having difficulty filling out forms and navigating the "roadblocks" of the social services system to get what they needed. For three patients, managing their lives and health care was a full-time job. The consequences of improperly filling out forms are not insignificant and inconsequential if patients are denied services when they are eligible for them. Several of the patients who were interviewed did not seem to be curious or inquisitive about their health because they were worn down by the never-ending effort required to "get by." At least two patients had recently experienced the death of a family member and wondered out loud if they might be next.

A few of the 22 patient interviewees were able to negotiate the maze and tried to live a healthier life, but still needed some assistance. Some had supportive relationships with friends and family. Many patient interviewees described their full and meaningful lives, in which they tried to give back to the community. Some unemployed patients sought out new experiences and volunteered their time and services. Surprisingly, considering that all those interviewed were patients at a free clinic, most of the interviewees expressed satisfaction with their health care and few felt that they needed more health information.

It was beyond the scope of my study to determine the cause of what appeared to be a decrease in accessing information via print or computers among the older adults, but it would be a useful topic for future study. Additional issues were raised that could not be fully answered and that warrant further investigation. One was the effect of mental illness and emotional upset on patients' mental status and cognitive ability to process information. Several of the patients between the ages of 55 and 65 spoke about how they used to read more than they do now, and that they now depend on family members or others to help them remember things. Some of the patients in that age group also reported health conditions that appeared to be job-related injuries, although the patients were not receiving health insurance or social benefits as a result of their injuries. The findings for this age group of patients would have major policy implications, if a larger study substantiated those issues. For example, the discussions on health-care reform considered and rejected the option of extending Medicare to those ages 55 and older. A second issue is the current discussion about raising the retirement age and the age at which one can receive Social Security. For patients such as those in this study who are waiting for their 65th birthday to receive Medicare, or their 62nd birthday to receive Social Security, a further delay in receiving benefits would be a burden.

CHAPTER 5: THE HEALTH-CARE PROVIDERS' POINT OF VIEW

"You never know what you're going to get, walking through the door, on any given day."
—Felicia, nurse manager at the clinic

From the beginning to the end of a clinical encounter, health-care providers are gathering information from the patients, making assessments, and imparting information to patients. When giving instructions to the patients about how they can maintain or improve their health, providers frequently gave anticipatory guidance about health challenges in the future (Kuo, Frick, Minkovitz, 2010). This scenario could apply to patients who have diabetes, where, for example, providers show patients how to perform self-care at home, such as how to test for blood sugar, or give practical information about how to take drugs. Providers also alert patients about warning signs, such as symptoms of stroke, and tell them when to seek emergency care. All of this advice involves educational strategies. Unlike many other educational encounters, the clinical encounter occurs intermittently when patients may be anxious, emotionally stressed, ill, uncomfortable, or otherwise beset with conditions that decrease their ability to take in, comprehend, and remember information given to them.

This chapter presents the findings of the interviews and observations of 20 volunteer health-care providers at the clinic, and quotes from relevant portions of the interviews to present the major themes about health literacy and communication. On nine occasions, I observed the health-care providers interacting with the patients, usually at the end of the clinic visit. I interviewed two physicians, 14 nurses (among the nurses, one was a nurse practitioner and nine were registered nurses working toward their bachelor's degree in nursing) and four medical students. Most of the interviews took place at a table

in the large dining room near the doctor's office and the exam rooms. We sat off to one side and away from others so that the interviews were as private as possible.

Providers were asked questions about their education and work experience, with an emphasis on health literacy and communication. The interview questions and the focus of the observations addressed health literacy and health communication between adult patients and health-care providers. The health-care providers tended to share concerns and themes that were reflected in the medical and public health literature about health literacy. They repeatedly spoke about health literacy as a result of their training and continuing education. Therefore, their viewpoint, for the most part, came from an etic perspective.

Dr. Patterson, the medical director of the clinic, was well known in the community for caring for the poor. She had brown hair, was of medium height, and wore street clothes, not a white lab coat. She was always "on the go," dividing her time between meeting with patients, mentoring students, and soliciting money and resources for the clinic. She was a family medicine physician who worked full-time at a practice and volunteered to see patients twice a week at the clinic.

In addition to caring for low-income and medically uninsured patients, the clinic had a secondary mission to have students experience caring for the underserved. Dr. Patterson expressed the hope that the students would not only benefit from this educational experience, but would also continue this kind of service after they graduate. Any day that the clinic was open, nursing students, medical students, and public health students were all interacting with patients under the supervision of the professional staff. The physical floor plan of the clinic included a large open room with about 15 large

tables. This setup allowed groups of interdisciplinary students to meet frequently with a provider for brief discussions. In addition, the students were encouraged to discuss issues in multidisciplinary groups and to learn from each other. This educational process also came into play when both staff and student nurses interacted with medical students in the exam room, when student nurses taught first-year medical students how to do injections before a flu clinic, and when student nurses, a public health student, and medical students worked together to provide foot care for patients.

Of the nine nursing students, all but one were in their mid-20s and were very early in their clinical careers. All were matriculated students in a bachelor's degree program at a four-year college for their junior and senior years, having finishing their RN training at a local hospital. Most had some nursing work experience at a local hospital and were continuing to work full- or part-time during their study. Only one did not have any professional nursing experience. Most were at the clinic to meet the clinical requirement of a health promotion class at the college. They wore scrubs, while the volunteer staff nurses all wore street clothes.

Three of the four medical students interviewed were first-year students and were just starting their classes at the medical school. The fourth medical student, Tom, had completed his academic coursework and was looking forward to starting clinical rotations as a third-year student.

Awareness of Patients' Literacy/Health Literacy

In preparation for this study I volunteered at the clinic for three months and sought the input of the providers for the design of the study. To a person, they all thought that low health literacy was a major problem. Health literacy has become a buzz word in

medicine and nursing. A recent Medline database search yielded 4,721 articles in which health literacy was mentioned. Students hear about it during their training; providers talk about it. Despite the evidence of increasing concern with low health literacy (see Chapter 2), there are relatively few empirical studies about the topic that guide providers in how to resolve the problems patients face with low health literacy. Mackert, Ball, and Lopez (2011) found that health-care providers who participated in health literacy training initially overestimated their knowledge of the topic. Within the various health-care fields, the most comprehensive guides to how to address health literacy in practice came from nursing journals (Cormier & Kotrlik, 2009; Fisher, 1999; Schaefer, 2008).

All of the five staff volunteer nurses I interviewed expressed concern about the issues of low health literacy and used strategies to maximize communication in their interactions with patients. For example, Nadia, a nurse who was also a certified diabetes educator, said:

> Sometimes you can't tell if that's a sight issue or a literacy issue. ... But the easiest thing is to give them some information and then say, "Tell me what that means to you. Can you explain to me how you're going to do what I just explained to you?" By what they tell you back, you can tell if they are on the same page with you or not.

Two other nurses, Rachel and Emma, did not make any assumptions about patients' literacy levels and read all the intake forms to all the patients that they saw because, as they explained, "you can't tell by looking" which patients might have difficulties in reading comprehension. Carol, who was a nurse educator, has worked in a variety of clinical health-care positions and thought that more of the patients at the free clinic were honest about their literacy limitations than in other venues where she worked. At the time of the interview, she was teaching health literacy to student nurses at a local

college. Felicia agreed with Carol that clinic patients were more open about their literacy challenges and that they did not offer excuses such as forgetting their glasses if they could not read or complete forms.

Health literacy seemed to be threaded throughout the curriculum for the student nurses and was also a frequent topic of discussion at the clinic. Despite this repetition, all but one of the student nurses I interviewed expressed less confidence about caring for patients with lower literacy or other difficulties with comprehension than the experienced nurses. Cathy, the student nurse who did feel ready to address low health literacy in her practice, had a brother with dyslexia who routinely received special accommodations in high school. Cathy helped her brother with his school work, frequently asking him if he understood what he had read. This life experience helped to put her at ease helping patients at the clinic who may have had low literacy. She said, "To me it's not a big deal if you can't read. But if you really have a problem with reading and you struggle with comprehension, you know, we can help you with that."

Many of the students and health-care providers with whom I discussed health literacy blended issues of reading comprehension and health literacy. However, Dottie, the nurse practitioner, made a specific distinction between the two. When questioned about how many patients have low health literacy, Dottie, a nurse practitioner, claimed that it was close to 100 percent of all patients. She had volunteered at the clinic for over a year and then worked for pay at an outpatient clinic at a local hospital where, she said,

> the general educational level, on the average [among patients in my hospital practice], is much higher than at the [free] clinic. And I still have interesting times explaining to people what some of their health options are ... And what I found was that, there was also, even in our most educated people, there was a tremendous gap in understanding certain, sometimes very key aspects, of people's care. And it's not so much that it's a technical literacy [problem].

> Sometimes it's more of an overload of information. And [I deal with it by using] the art of understanding how another person processes information and also the magic of repetition.

Dr. Patterson commented on patients with low literacy:

> Since I've been here, I've been much more sensitive to it, and also in my other practice. Some of the people here, I don't ask them any more because I know they can't read. The bottom line is that demographically, probably 50 to 60 percent of our patients are functionally illiterate here. Either because of mental illness or never learned or can't learn or whatever ... We do a lot of verbal stuff here. What I often do is write things down and then explain them and say, "Is there anybody in your life that can read this with you and help you?" In terms of finding out who is illiterate and who isn't, again, if you ask with kindness, people generally will let you ask them anything. And will give you an honest answer for anything. I didn't always realize that when I was first working here. I was taking care of a lot of patients that couldn't read and never knew it, because I never asked. But the literacy issue makes it very difficult, very difficult to give them something to take home ... And that's what we do here; sometimes say it over and over again. I'm amazed that even here, even with homeless people, when they get the proper teaching, the proper support, they get their blood sugars under control. I still don't believe it when it happens, but we see it.

Provider-Patient Communication

The patient-provider communication that I observed in the clinic included providers asking patients questions, quickly prioritizing what they needed to do for the patient during that visit, and making a medical plan that they then communicated to the patient. The medical plan could include diet, exercise, referrals, medications, blood testing, risk reduction, and numerous other strategies. The providers appeared to make considerable efforts to insure that the patients comprehended what they needed to do. For example, I observed the following interaction when Dr. Patterson and Lisa talked about food choices. Dr. Patterson said:

> If you need to make choices about food, quick and dirty, things that are white are usually worse for you than things that are green or brown. White is not a good color, especially for bread and things like that. Chocolate donuts don't count. Green vegetables are lower in sugar than the other ones. White potatoes are bad. Cauliflower is an exception; cauliflower is OK. So go with green. And then after

> green, go with things that are brownish. And then things that are orange and then things that are white are the highest in sugar content and starch. Green is the lowest. And when you're dealing with bread and stuff, brown is better than white.
>
> Lisa said, "Better than white."
>
> Dr. Patterson said, "What's that?"
>
> Lisa said, "Oat and wheat is better."
>
> Dr. Patterson said, "Oats and wheat are better and wheat is better than oat."
>
> Lisa said, "All right."
>
> Dr. Patterson said,
>
> Anything that is whole grain is better. Just because it's brown doesn't mean that it's wheat. Sometimes it's brown with a whole bunch of molasses in it. So you have to read ahead and look for whole grain. The buzz word is whole wheat. As long as you can tolerate wheat, that's the way to go.

In my observations of providers at the clinic, many of them appeared to emulate Dr. Patterson's high levels of concern and empathy for the patient. Nadia, the nurse/certified diabetes educator, commented,

> Consider what is important to them after asking a few questions. And like we did with that person (Ethan) I had that day, jump on some of the things that they acknowledge, because that's something they are invested in.

Nadia asked Ethan about the strategies he used to plan his diet. When Ethan mentioned portion control, Nadia suggested that he wait 15 minutes before eating anything more to determine if he was still hungry.

During their nursing school classes and clinical rotations, the nursing students described how they learned to communicate with patients using "therapeutic communication," a technique that included the use of open-ended questions to encourage patients to express their feelings and ideas. Cathy described therapeutic communication as "letting them [the patients] give us information as opposed to us prying into it. Let

them tell us their own experience, from their own perspective and what they're going through."

Felicia, a staff nurse, offered a working definition, saying, "[Therapeutic communication] has to do with counseling and supporting people and learning how to talk with them."

Truly effective communication takes time, however. Dr. Patterson was pragmatic about how much time she could spend listening to patients about their problems and concerns:

> One of the things that I was taught was ... It doesn't always work in real life ... was to let the patient take control of the interview and be very open-ended. And we still teach the medical students that, but in the real world, it only works to an extent. Because the reality is that, in a for-pay practice, we are required to see more and more patients per day. And if we spend too much time letting the patient give you the history without direction, your day is ruined ... . So for most of my career, I have felt conflicted about taking control of the interview, being efficient ... Here, at this clinic, I try as much as I can to be open-ended with the patients. But our patients, most of them, have been so marginalized from medical care, that they actually need someone who is organized to get them organized, so that they can begin to sort out their medical issues. And sometimes I actually have to be very closed-ended and prescriptive in order to help them figure out exactly what has been going on for years and has not been managed. You know, I think what I've found out over the years ... the most important thing about provider-patient communication is that if you establish ... the first minute that you walk in the room, that one, you have their best interest at heart and two, that you will be kind to them, basically you can say and ask them anything. And I think the key to being a good doctor is to be able to establish that, not only with your words, but your whole person ... In my faith tradition, they have this saying, "Speak the truth with love." And that, to me, is the ideal, my benchmark.

Like the nursing students, the medical students had also been taught somewhat idealized communication strategies that were being challenged in the "real world" situation of the clinic. The medical students that I interviewed spoke about the instruction they received in effective communication strategies. Monica, a first-year medical student,

described the role-playing sessions that followed a medical school lecture about communication:

> We had small group sessions, in our P.O.M. [Practice of Medicine] class, that focused in on how to speak to a patient and how to deliver bad news ... And how to ask certain questions appropriately or how to speak to a patient who is inappropriate with you. That was about it as far as communication.

Tom, a third-year medical student, had been coming to the clinic for two years and spoke about the differences between the idealistic communication strategies that he had been taught in his first two years in medical school and the reality of communicating with patients in clinical practice:

> I suppose from an academic standpoint, we talk about it in the first two years. And then it's really put into practice in the second two years, when you're actually in with patients every day. And now and again, you kind of get a chance to step back and talk about it in the abstract. Things like what elements of this interaction were positive and negative. But by and large, you really get sucked into the medical part of it. The discussion between a mentor and a student is the medical aspects, rather than the human aspects.

Felicia, a staff nurse, appeared to be a master of communication, both when directing other providers and when interacting with patients. She was frequently asked by other providers to calm patients who were distressed. I asked her to describe her analysis of the elements of communication. She concisely described what happened when she presented new information to patients:

> You write it down carefully. You repeat it. You have them repeat it. You show them. That's really after you figure out if they understand, if they can read. Yes or no, and then depending on what you get back from that, you have to adjust your approach. Minimalize the information you share and simplify it. Draw pictures or write it down.

Other providers also emphasized that effective communication means limiting the amount of information provided and repeating it as necessary. When Dr. Patterson spoke with her patient Lisa about nutrition, she started by saying, "I want to strike a balance

between overwhelming you and not giving you enough." Tom, a third-year medical student, echoed Dr. Patterson when he said, "I always feel that less is just more ... A couple of things to carry away, instead of a whole education."

Carol thought that limiting the amount of information was the most challenging part of communicating with her patients, especially when the patient may not return to the clinic, as she described:

> Realistically, to limit the amount of information we give them might not be in the best interest of anybody. We might have to do, what we used to call in the hospital, emergent teaching, to make sure that we at least covered everything once. And then if you do have the luxury of getting the patient back, then we can break it down further.

Several providers used pictures to help patients remember details, as Mary described:

> A lot of times, a patient has had surgeries or they had procedures. When they're getting those procedures, I'll go on the Internet and print out a picture for them and kind of describe it that way. You can get creative.

Monica, a first-year medical student, was the most enthusiastic about drawing pictures because that was how she preferred to learn information:

> I mean, I really like drawing pictures. I do that when I study. I think that would be really helpful for patients as well. I can't understand something unless I see it, so I think a lot of people are visual in that aspect and that might be helpful too.

In contrast, Dottie, the nurse practitioner, was skeptical about drawing pictures and preferred to tell stories to make her point. Houston et al. (2011) document the benefits of narrative communication, such as storytelling or testimonials, for health promotion. Dr. Isaac also did not use pictures and stated why:

> If I were a surgeon and going to replace a valve or fix a joint or operate on an ear or whatever, I might draw pictures. But basically I describe medicines, counsel

> patients, prescribe medicines and I've not really felt that diagrams would be that helpful.

Several of the providers described using a technique of asking the patient for feedback on what they want the patient to remember, to ensure that patients understand their health conditions and what actions they need to take. George, a student nurse, and I discussed how patients may not admit that they don't understand. He gradually realized that asking a patient for concrete feedback with the question, "What did I just tell you?" is better than asking, "Do you know what I'm talking about? Do you know what I mean?"

The nursing students were enthusiastic in their efforts to achieve high levels of communication and understanding with their patients. Vicky spoke about working at a local hospital and using videos to prepare the patients for their home-based self-care after discharge from the hospital, saying, "We do a teaching session before the video. And we have them watch video. Then we do a teaching session where they can show us the tasks."

Dottie, a nurse practitioner, was concerned that patients might be offended unless they were asked for feedback using very specific language that suggested working together in a partnership, as she explained, "It's my perception, somebody that thinks you're doing a 'repeat after me' sort of thing that it immediately means, 'You don't trust us.'"

Medical jargon was also a challenge for the students to put into plain language. First-year medical student Gary, for example, said how difficult it was for him to interact with patients because at the same time he was learning medical terminology in class he

was trying to communicate with patients using everyday language at the clinic. In medical school, he explained,

> For shortness of breath, you report what you find…They don't want you to say, "Normal breath sounds." What does normal mean? So you have to say, "vesicular," they diminish as they go out through the periphery. So you have to say, "Strong and symmetrical chest expansion."

Gary described how when he came to the clinic:

> As a student, it's very tough because, for you, what you're first learning, it's new jargon. So you're using it. You don't consciously ... It just slips out. When I was talking today…they're looking for capillary refill. And I was just ... I was trying to explain it [to the patient]. And then I said something about oxygen perfusion.

Tom, the third-year medical student, commented on switching back and forth from medical jargon to plain language:

> We just did an intake questionnaire with a patient, talking about the past medical history. And rather than, you know, ask about cardiomyopathies or cardiac events, you say, "Have you ever had any heart trouble?" I generally try and err on the side of caution and try to speak to the lowest common denominator. I use organs, rather than conditions, you know. "Do you have problems with your liver, your kidneys?" I feel people can generally localize, if they're told to localize problems at places in their body, rather than actual ailments.

At the hospital where she works, Joyce said,

> A lot of my job is, every time the doctor leaves, is to go back in and explain it in layman's terms ... The Foley catheter—there's a tube going into you and your urine is going into a bag.

Rachel, a nurse, also commented on the need to simplify medical jargon, said:

> Meeting the patient where the patient's at. You're always trying to assess for that, most nurses are ... You always kind of have to quiz that. Determine the patient and their educational level. Do they need simpler, less complex explanations or are they familiar or had a diagnosis for a long time? They may be quite familiar with a certain amount of the medical verbiage that is associated with it. Conversely, if you're newly diagnosed with something, you're not going to be real familiar with it. You always have to determine their knowledge base in medicine and the culture.

The providers also demonstrated sensitivity to their patients' feelings. Dr. Patterson was explicit in how she models respectful, empathetic provider-patient communication to build trust with the patients. Dottie, the nurse practitioner, reflected on Dr. Patterson's leadership in her relationships with patients, students, and staff at the clinic:

> The patients themselves are returning and they almost help in the education by saying how much being treated as an individual with respect means to them, even when they get insurance ... They continue to come back, because even though they sometimes have one, two, three hours waits to see somebody, when they're seen, they're like the only person in the world. And we will spend some time with them to do everything that we can within that context of that visit ... And get other things started for them. And I think they value that a lot and I think the med students seeing that, start to understand more from that interaction and the patients telling them what it means to be respected, what it is. And then you have Dr. Patterson, who is just kind of, you know, preeminent in terms of being able to establish relationships with people. When they see her in a room, they see her really caring for somebody who is for all the world like they washed up on the shore of a deserted island. For example, you get somebody with particularly bad diabetes or other vascular disease. Their legs, they get horrible leg wounds, just awful toes, you know, and things on their feet, lesions and what not. And Dr. Patterson is saying, "Oh these sores . . ." There's a way that she talks about your feet, your wellness. And it becomes clear to other practitioners in the room that she's not just talking in terms of treatments, or trying to access other providers, like, social workers, for a problem here, a problem there. She does not see the individuals as a constellation of problems as much as a network of relationships. And I think it helps them.

Tom, a third-year medical student, offered a unique viewpoint on patient-medical student interactions at the clinic:

> I've often thought that there's a unique parallel here between students at the very start of their careers, essentially on the outside of medicine looking in, and patients who are also on the outside of the medical system without real access to providers or to the system at large. And so you have two people who are outsiders, essentially, meeting together. I think there's more going on in these interactions than you'd assume. I feel that's always been a way to connect with patients, relate to them ... And like you've said, once you relate to somebody ... once you realize that the person you're interacting with is also "on the outside looking in," it's a shared experience ... And you get great stories from people here, how that [lack of health insurance and poverty] plays out day-to-day in daily

> life. You learn a lot about what that means when they say 47 million people are without insurance. You get to interact with a couple of them each time you come down. For people getting into medicine, it puts a human face on things.

Nonverbal aspects of communication were also described by the providers as important to put patients at ease and gain their trust. Nadia was aware that eye contact is not important for some people: "You and I will assume that if somebody's not looking at us, that they're not hearing us. In fact, in some cultures, they're attending very well."

Cultural Aspects of Communication

Adherence to the federal *Culturally and Linguistically Appropriate Standards* (CLAS) (see Chapter 2) was at times a problem at the clinic. The CLAS guidelines include providing translation services for patients with limited English language proficiency. This group includes those who can understand and speak some English, but need help with describing their symptoms and understanding complex issues, such as drug dosages. A number of newly arrived refugees came to the clinic, not because they lacked health insurance, but because they had difficulty negotiating the United States health system. I observed such patients on three occasions during my five months at the clinic. One female of Asian descent spoke very limited English and visited the clinic for a chronic condition. She came by herself and so did not have any translator. Simple phrases in English and body language were used by both the patient and providers for communication.

I also observed a brief encounter one afternoon between the clinic receptionist and two Somali women in native dress and their five young children. The women walked past the receptionist into the waiting room, causing a commotion, and demanded to speak to the doctor. They were not patients at the clinic, but had prescriptions from another clinic

that they wanted to get filled. The staff used more sign language than spoken English to make the women realize that they could not get their prescriptions filled at the clinic.

Some of the patients spoke Spanish, a language in which a few of the staff and students were proficient. Even with Spanish, some patients arrived with friends to help translate. José, a male patient whom I interviewed, was of Puerto Rican descent. On one occasion, he accompanied a younger Latina woman to the clinic. She apparently did not speak English and he served as her interpreter during her entire visit. She did not appear to be ill at ease, but there might have been some sensitive questions and answers during the intake and exam that could have been uncomfortable or embarrassing.

New York State regulations mandate that hospitals provide medical translation or language access for patients with limited English proficiency [10 NYCRR 405.7(a)7]. One staff nurse and one student nurse who both worked at the same local hospital mentioned using CyraCom at the hospital. It is a telephone interpreter service for more than 140 languages and dialects. Unfortunately, the cost of such a telephone translation service was far beyond the capacity of the free clinic. The patients and staff simply did the best they could, given their environment and resources.

Challenges to Health Communication at the Clinic

The intermittent nature of patient contact was a main theme of the provider interviews, although some patients were certainly "regulars" at the clinic. The providers were concerned about patients running out of their medications and if the clinic had enough medications in stock to supply the patients. Patient literacy and numeracy knowledge and patients' ability to plan came into play after they left the clinic and were responsible for their self-care. Another theme was frustration about the "chaos" or relative lack of order when the clinic was open.

The strength of the clinic was the staff's recognition of the challenges facing the patients they saw, which included homelessness, mental health and substance abuse issues, or simply a lack of health insurance. Social service agencies also required pages of medical documentation for referrals, a lengthy task that the clinic staff fulfilled for many patients. Dr. Patterson believed that clinic patients had more support available to them than patients in other clinics and private practices. She and the other providers offered more than just medical care by listening to the patients; helping with housing, food, and legal help; and offering spiritual support. She described the clinic as offering "boutique" care for the poor:

> This clinic, grassroots as it is, models that better than the private practices that I've been around. We do have social services and mental health. So if we identify a mental health need that someone hasn't had met elsewhere, we can plug them in with a social worker. If someone comes and tells us that they're hungry, that's one of the needs we identify here. We can give them a bag of food and get them food support through the pantry next door. We have a second-to-none certified diabetes educator here. And it's an interesting model, because in my private practice, if I have a patient with diabetes, if they can't afford to go to diabetes teaching, then it's me or it's nothing. And here, if I have twenty patients to see and I'm the only MD, here I can continue to function at my highest level of function as a physician,

which is diagnose, render judgment and treat. And then I can say to the diabetes educator, the patient in room two needs ... You know, the other thing that's wonderful here is several patients who have been able to get more stable lives, establish more stable lives. And I think that we had a role in that, getting insurance and moving on. But they come back to thank us and say, you know, you really helped me get back on my feet or get motivated. We have patients that come here that are actively drunk. We accept them; we're present with them and keep prodding them. They check back and a couple of them have stopped drinking. We had one guy who got himself off cocaine for a while and relapsed, but he tries. Before I started doing this work regularly, I never believed that people would actually do that ... We had one guy who came back and he said we changed how he looked at the world.

CHAPTER 6: CONCLUSIONS

This dissertation is a study of the health literacy and health communication between patients and providers, as well as the health education strategies used at a free medical clinic in a mid-sized upstate New York city. The data collection was completed at the end of 2009, just before national health-care reform was enacted. Thus, the lessons learned in the dissertation relate not only to the original questions of health literacy, education, and communication for adults, they may also provide a qualitative snapshot of the low-income and uninsured patients in a free clinic just prior to this major policy shift. This study was based on participant observations in the clinic, interviews of 22 patients and 20 health-care providers, and direct observation of provider-patient communication in nine instances.

The research questions and major findings of the study coalesce around two major components. The first addresses the health literacy of patients and the communication of health information between patients and providers, which is essential to patients following through with recommended health information and advice. The second component is broader; it examines how health education for adult patients draws on and, in turn, informs adult education strategies.

The Patients' Viewpoint

The data presented in this study substantiate the broad definition of health literacy issued by the Institute of Medicine (2004). Health literacy encompasses more than simply literacy or reading comprehension. To my surprise and the surprise of the providers at the clinic, low literacy, specifically limitations in the ability to read and comprehend the written word, was not a problem for most of the patients. This study did not support the

expectation that at least half of the patients would have low literacy, according to the 2003 National Assessment of Adult Literacy survey. This result could have been due to the relatively small sample size.

I used a variety of ways to assess reading and oral comprehension during the interviews, including having the patient read the informed consent form along with me; observing the patients' ability to fill in various forms, including the consent form; and noting patient comprehension of the self-care requirements during their clinic visits. Only two patients showed overt signs of low literacy. One laboriously signed his name on the consent form; and another misspelled her last name on the consent form. Neither had graduated from high school.

In contrast to the expectations of the providers at the clinic about patients' education, only three of the 22 patients had not finished high school. Three others had earned a GED and 16 had received a high school diploma. Of the 16 high school graduates, five had some college, two had four-year degrees, and one had a master's degree in bilingual education. Close to half were quite well educated, which is a higher proportion than that of adults in the city in which the clinic is located. Nevertheless, a majority of the patients had at least some difficulty with effectively accessing, comprehending, and following through on health information. Reading ability, simply being able to decode and comprehend written material, wasn't the primary factor contributing to miscommunication. Other issues, such as substance abuse, mental illness, and financial worries limited the patients' ability to focus on printed materials, especially the many forms that patients' needed to complete. The ability to read, pay attention, and comprehend verbal health information was compromised by stress, mental health status

and compromised cognitive ability. Such a lack of ability was more salient at the free clinic.

After considering the patients' perspectives about their health literacy, I concluded that navigating the medical system could be a challenge for anyone. For those without health insurance, finding out where to obtain care, and where and how to fill drug prescriptions was incredibly frustrating. For those who might qualify for Medicaid, the application process can be daunting. Many of the patients wondered whether to go through the process of applying for Medicaid, or how to pay the spend-down after being accepted for Medicaid coverage. Many times Medicaid coverage was episodic. One patient lost his coverage after receiving a workman's compensation payment and was reapplying for the benefit. When another patient received Social Security widow's benefits, her income was slightly more than the upper income limit, which disqualified her for Medicaid. She ended up in three different emergency rooms during one month and was subsequently sued for $30,000 in unpaid hospital bills.

Ethan described encountering "roadblocks" and "stop signs." He was not sick enough to qualify for Social Security disability even though he thought his mental health issues, Crohn's disease, and diabetes were severe enough for him to qualify. He thought that the system was slanted against a 62-year-old male. Other patients like him experienced a gap in health insurance coverage in their late 50s or early 60s when they became unemployed and were no longer able to find or perform the type of work they once did. This age group (55–64 years) would have been covered if Medicare eligibility had been lowered to age 55 under the recent health-care reform legislation (Hulse & Pear,

2009). However, this provision was not included in the Patient Protection and Affordable Care Act (P.L.111-148) that was enacted in 2010.

Patients who have been employed and received health insurance benefits may more acutely recognize what benefits are lost when they become uninsured. Many of those patients have disabilities that make it very difficult for them to work, but are not severe enough for them to qualify for Social Security Disability. They will probably continue to come to the clinic until they are eligible for Medicare.

The patients were resourceful about accessing community resources, especially when seeking help for paying for medications. Most of the patients who were interviewed seemed to have at least some knowledge of services offered by outside social service agencies. One patient recently released from prison worked diligently at "jumping through the hoops" in order to acquire health insurance, housing, and employment. Several patients expressed that it was difficult for them to understand or negotiate the system, especially when asked to fill out pages of forms. Patients enlisted the help of family members, caseworkers, or health-care providers at the clinic to fill out the required forms. Dr. Patterson and her staff spent hours filling in forms for patients to receive Medicaid, Social Security Disability, and/or other emergency assistance. Several of the patients interviewed did not seem to be curious or inquisitive about their health because they were worn down by the never-ending effort required to "get by."

Accessing Health Information

The 22 patients interviewed in this study were asked what they would do if they had any questions about their health after they left the clinic. If patient interviewees needed additional health information, they usually asked others and relied less frequently

on print or the Internet. Many of them said family, friends or health-care providers would be a source of information if they had questions about their health or treatment. Eight patients replied that they would ask a health-care professional, and nine would ask a friend or family member. Even though a friend or family member may be in the health-care field, usually working as a nurse's aide, they may have no better understanding than the patient about what happened during the clinic visit.

Thirteen patients interviewed for this study had some experience with using computers, sometimes only to play games. Nine of them knew how to search the Internet, but only two patients had actually used the Internet to look for information about their medical conditions. The low proportion of patients using the Internet to access health information may be due to a combination of lack of money for computers and, therefore, Internet access, and the high number of older patients included in the study sample.

Health Communication

A number of points emerged about the health communication strategies used by providers in the clinic. It was clear that health-profession students at the clinic were being instructed in techniques to improve patient communication. The emphasis in training students about health communication varied with the health discipline. The nursing students, especially, learned about communication strategies in the classroom and routinely applied their knowledge in clinical situations. Although the student nurses had not spent much time at the clinic, most worked at a local hospital. They described how after physicians spoke with patients at the hospital, the nursing students rephrased and explained the information given by the physician, using clearer and simpler language that the patients could understand. They expressed frustration when discharging patients in

that too much information needed to be covered in too little time. The patients at the hospital had a questionable ability to optimally process information and ask questions while listening to medication and self-care instructions.

First-year medical students received a lecture about communication from one of the physicians at the medical school and then practiced communication strategies with role-playing. Compared with the nursing students, however, the medical students' primary focus appeared to be on learning medical knowledge; developing communication skills was secondary. While an analysis of the communication instruction in the curricula of nursing and medicine was beyond the scope of my study, it appeared that the nursing students received more explicit instruction in communication strategies than did the medical students.

The first-year medical students were eager to interact with patients. Dottie, the nurse practitioner, commented that the students' idealism and enthusiasm at times did not result in effective communication of health information. Tom, a third-year student, described the scenario this way: "Students at the very start of their careers (are) essentially on the outside of medicine looking in."

The first-year medical students seemed to learn a great deal about effective communication by observing the senior providers at the clinic. Dr. Patterson believed in exposing these students to serving others. They should also be exposed to health literacy and patient communication issues early in their schooling. The advantage of having a multidisciplinary group of students at the clinic was that they learned from each other while observing each other's health communication.

The more senior health-care providers were remarkably effective communicators, yet they reported that they had to abandon the "ideal" communication strategies taught in school and adopt a more real-world, less open-ended, and less verbal interaction with patients. During my direct observations of Dr. Patterson interacting with patients, she practiced HL as a health-care provider when she listened attentively to each patient, limited the amount of information communicated to the patient, and worked to provide a shame-free environment at the clinic. As the providers explained, the time allotted for an office visit was limited. While at the clinic, the patients presented with multiple, serious health problems that had often been ignored for a long time, due, in part, to the difficulty of obtaining health care.

Adult Education and Health Care

The providers at the clinic were the educators of vulnerable, stressed patients. Most providers did see themselves as educators. A few did not. The clinic setting provided an excellent opportunity to learn more about how adults learn and how to communicate with people who are stressed. The clinical encounter shared many aspects of adult education, with the provider in the role of educator and the patient in the role of student. Both patients and adult learners have concerns about their health issues and how to resolve them. An adult educator could help staff and students to understand communication successes and challenges. Adult educators could learn a great deal about the clinical issues that many of their adult students face. In the scholarly literature about adult education, physical challenges to learning, such as poor vision or hearing, psychosocial emotional issues, and student financial difficulties are rarely addressed, yet they may be among the most difficult barriers to adult learning.

Health-Care Providers as Educators

I was impressed by the efforts of health-care providers to intentionally overcome the mental-health, substance-abuse, stress, and time-constraint barriers in a busy, crowded clinic environment. When clinicians have patients with multiple diagnoses, they must decide which health behaviors to prioritize at that visit. The health-care providers realized they might only have one opportunity to interact with some patients; therefore, they covered the basics, often not having the time to address the finer details of what patients should try to do. In all of this controlled chaos, the health-care providers created learning opportunities for students by modeling excellent communication strategies.

A key aspect of this research project is not only literacy, but access to knowledge. The low-income and uninsured patients of this study needed to understand themselves and the world around them. The patients specifically needed to address their health-care needs at the clinic and outside of the clinic. The providers at the clinic intuitively understood that if the patients had access to knowledge, they would also acquire power over their health.

In light of the limited time frame for patient-provider interaction at the clinic and the considerable amount of information that patients must understand about self-care after the clinic visit, it would be useful to have printed health education materials and videos about various topics available in the waiting area. The small study on health education materials presented in Appendix B could be helpful in guiding the choice of materials to be distributed to patients. Most of the written educational material at the clinic was filled with dense print at too high a reading level. Moreover, most of the printed material described health problems, rather than clearly explaining what patients

needed to do about them. The study examined five handouts and a DVD. When asked, patients were helpful in identifying the print materials that they preferred. The patients who viewed the DVD overwhelmingly expressed their approval of its use as a health education strategy in the clinic. A DVD library, even in a very financially stressed clinical setting, could be created to help patients to learn more about their diagnoses and provide motivation to change their behavior.

Answering the Research Questions

The patients' perspectives on their health literacy did not usually focus on reading ability, but on the "roadblocks" and "stop signs" that were encountered in accessing health care. These roadblocks included emotional health and procedural issues when applying for social services. Since most of the 22 patients had a chronic illness such as hypertension, diabetes, or asthma, they were familiar with the medical terminology about their diagnoses. Patients understood the various printed materials and especially the verbal communications from the providers. They seemed willing to ask questions if they were unclear about their diagnoses or self-care tasks. The main obstacles to communication were the dense print and high reading levels of information sheets and handouts available at the clinic. Instead of print, the patients seemed to prefer face-to-face communication with providers. Three patients mentioned reading books about health topics at home and only two of the 10 patients who used computers had accessed health information online. Health-care providers successfully used communication strategies when interacting with patients. By limiting and repeating information, and soliciting feedback from the patients, providers ensured that their patients left the clinic knowing what their health issues were and what to do about them.

The Clinic Provides More Than Medical Care

In addition to providing a high level of health care, the clinic made every effort to help patients overcome communication barriers that resulted from increased stress due to poverty and cognitive challenges. The clinic performed physicals so that patients could satisfy requirements to apply for work, school, and housing. The clinic also provided more than health care. It is located next door to a food pantry and both the pantry and the clinic provided referrals to social service agencies. A social worker was available for personal counseling. All of these efforts improved the patients' comfort, as well as their health literacy and health communication.

Some patients had been coming to the clinic since its doors opened in 2007 and now had the benefit of a long-term relationship with Dr Patterson. First-time and returning patients experienced positive social interactions and conversations as a respite from getting through their day. The clinic could also be simply a place to hang out. Patients frequently stopped by for coffee, doughnuts, and conversation. One day, a priest sat in the waiting area and talked with patients. The clinic staff provided empathy and support to help patients achieve their goals, including helping the patients fill out the many forms required for eligibility for various services.

One of the provisions of the recent health-care reform bill that was enacted in 2010 was mandated health insurance coverage. This study demonstrated that while health insurance is very important, poor patients and those with lower health literacy will require more than a card allowing them to receive health care. If universal health-care coverage took effect tomorrow, it is possible that many of the patients would qualify for Medicaid. Even with health insurance, however, access to health care might be difficult

because having an insurance card does not guarantee access to health care. There will still be a need for the clinic.

Recommendations

Universal Access to Health Information

Similar to building ramps for buildings and using closed captioning for telecommunications, health information can be made more accessible. The clinic followed universal precautions when treating patients and drawing their blood, assuming that any patient could have a contagious, blood-borne infection. We could think of health literacy in a similar manner and use universal precautions when educating patients, assuming that any patient could have low literacy. Although many patients have adequate or above adequate literacy skills, when they are sick or stressed, their health literacy is temporarily compromised. If low health literacy is recognized as a common occurrence, it would be wise to take the precautions of using clear communication with all patients, not just patients with limited literacy. Similar to disability studies recommendations, support for learning can be offered while presuming that patients are competent and have the ability to learn (Biklen & Burke, 2006). The educators take on the responsibility to provide opportunities to learn and provide information in creative and alternative ways. The goal is to make sure that all patients understand the "whats, whys, and hows" of treatment.

The clinic could adapt and improve printed materials by looking beyond simple grade-level readability standards to create or choose materials that are easy to read and that help motivate patients. Printed handouts can be easily modified to include more white space, and clearer directions and graphics that appeal to people from a variety of

ethnic backgrounds. The content of handouts can be modified to emphasize desired patient behaviors. The clinic providers did try to simplify a handout about hypertension, the "bullet" handout described in Appendix B. Four handouts about hypertension were available at the clinic and offered patients a choice of printed material.

The clinic has an older model laptop that the patients could use, but it did not have Internet access for patients. Patients might be receptive to computer instruction if it was specific to their needs for information and available in the clinical setting. If Internet access became available, volunteer educators could work with interested patients to find medical information online.

Dissemination of health information in accessible formats could be enhanced using effective adult learning strategies. Adult educators and clinic providers could learn a great deal from one another. Adult educators could tailor some of their curricula to include more content on health-care issues, such as reading drug doses or understanding informed consent. One role of an adult educator is to have learners integrate new skills and knowledge with what they already know. Another role is to have learners practice and improve their self-advocacy skills. Adult educators could serve as mentors to health educators to promote these skills with patients. An adult educator could revise the clinical intake forms and printed educational material to make them more readable and usable. Printed educational material could be recorded and then played back by the patient. An adult educator could work with the patients and discuss topics suggested by them.

This research may contribute to the advancement of treatment for low-income patients who are vulnerable and marginalized. This study may also reform existing policies in various health-care settings by emphasizing the importance of health

communication and literacy in providing patient care. The interviews and participant observation show that excellent patient care can be provided at a free clinic operating on a limited budget.

Study Limitations

Patients and health-care providers from a single downtown site were recruited, a limitation in geographical scope. Results and conclusions may not apply to other clinics, especially if the clinic charges a fee. A limited number of patients were interviewed and their experiences may not be representative of all patients at the clinic. As described in Chapter 3, I decided not to interview two patients—one who described himself as stressed and anxious and a second patient who appeared to be actively hallucinating. Not including these patients might appear to limit the study of patients with psychiatric symptoms. This potential limitation is somewhat counteracted by the inclusion of three patients with severe psychiatric diagnoses who were interviewed along with four with less severe diagnoses of depression and/or anxiety.

Future Research

More patients could be interviewed and informally assessed for literacy at the clinic to determine if the lack of low literacy in this study is a valid finding. As a result of this study, focused life history interviews are being conducted to document more of the patients' lives in relation to changes in their health status and the quality of their health care,

Some issues were raised that could not be fully answered and warrant further investigation. One was the effect of mental illness and emotional upset on patients' mental status and cognitive ability to process information. It was also beyond the scope

of this study to determine the cause of what appeared to be a decrease in accessing information via print or computers, especially among the older adults; this would be a useful topic for future study. Preferences of patients for print, video, and computer as sources of health information should be solicited.

Once health-care reform programs are in place, the status of the clinic and the patient population could be reevaluated and compared to the present day. Assuming that fewer citizens are uninsured or underinsured, will there still be a need for free clinics?

Appendix A

Patient Interview Guidelines/Sample Questions

Health seeking behaviors (at the time of the clinic visit and outside of the clinic)

Any comments about today's visit?
What are your greatest challenges in getting good health care and taking care of your health?
How could health care providers do a better job of communicating with you?
How could the health care system make it easier for you?
Do you feel that you need more information on your medical conditions or the medicine that you take?
How often do you have someone help you read medical information such as instructions or pamphlets?
How often do you have problems learning about your medical condition because of difficulty understanding written information?
How confident are you when you are asked to fill out medical forms?
The last time you needed more information about your health, what did you do? Is there someone you can discuss medical issues with (outside of the clinic/doctor's office)?
Any advice for other patients who come to the clinic?

Educational History
Formal: How many years did you attend school?
    Are you better at math or English?
    Have you ever had a problem with reading?
Learning Style: What is the best way for you to learn new things?
Informal: What topics interest you now? How do you learn more about them?

Health Insurance History
Have you previously had health insurance coverage?

Access to technology
Have you ever used a computer, PDA or MP3 player?
Do you have a friend or family member that uses the Internet?
Do you have a computer/Internet access where you live?
Do you know where the Internet is publicly available? Any problems using it?

Sample Questions for Health Care Providers

Have you ever received formal instruction about patient/provider communication?
Did it help you during your clinical training experiences?
Would you describe examples of successful communication during an office visit? Any examples that could have been more successful?
What percentage of patients have low literacy issues?
Do you have any strategies for communicating with patients with low literacy?
Do you have any comments about the AMA health literacy/communication guidelines?

Appendix B

Analysis of and Patient Preferences for Health Education Materials about Hypertension

This section describes a small study that I conducted to provide helpful information for the clinic. I evaluated the suitability of health pamphlets distributed by the clinic, and solicited patient preferences for the types of health education materials that they would like to receive. The final segment of the data collection involved eliciting patient preferences for methods and formats of health education materials. I wanted to understand more about patient preferences for video (DVD) media and felt that patients might benefit from learning about hypertension in a format other than print. Therefore, I conducted a short assessment of a video about hypertension with 10 clinic patients. I showed the DVD on a laptop computer that had been donated to the clinic.

I previewed a video about hypertension from the local county library. I also searched amazon.com and found three DVDs available for purchase. Their length varied considerably, from 93 to 60 to 12 minutes. Although the Amazon website did not allow me to preview the material, the description of the 12-minute DVD appeared to be appropriate for patients at the clinic. I purchased and previewed the DVD, which was an animated medical cartoon about hypertension entitled "Learning and Understanding About Hypertension: The Silent Killer." The inside jacket blurb read: "In this educational animated video you will find all the necessary information, presented in a simple and lively manner, to better understand what Arterial Hypertension is, its symptoms and consequences as well as the importance of its prevention. It doesn't matter what age you are, maintaining your good health is important to you and your family." The DVD was marketed by Animedhealth and offered audio language choices of English or Spanish, as

well as subtitles in both languages. It included African-American and Latino characters as health-care providers and patients, making it more culturally appropriate for a diverse audience. The shorter length of this video seemed appropriate because of the limited amount of time available to patients to watch the video in the clinic.

Ten patients with a diagnosis of hypertension consented to watch the 12-minute animated medical video about hypertension and were then asked to comment on the video. The patients were also shown five different handouts on hypertension and were asked which handout they preferred. Four of the handouts were available at the clinic and the fifth one was a printout from a website that offers easy-to-read health information. The Suitability Assessment of Materials (SAM) pinpoints specific deficiencies in printed material about health information (Doak, Doak, & Root, 1996) and was used to calculate a total suitability score for all five handouts.

Hypertension (HTN) is a common patient diagnosis at the clinic. The disease is often called the "silent killer," for good reason. Patients with HTN may not know they have it and may experience profound damage to their health before they feel any ill effects. The treatment of HTN includes counseling, mutual agreement on goals, patient adherence to the goals, and follow-up appointments. None of this can happen without both the patient and the health-care provider offering accurate information. The patient needs to describe all symptoms being experienced. The health-care provider should offer information specific to the patient's education and culture.

For this study, 10 patients with HTN were asked to visually scan five handouts about the topic and determine whether the handouts were readable, clear, and/or got their attention. This exercise was more than just determining if the patients could actually

decode the words on the handouts, because health education is about more than simply imparting knowledge; it is also about motivating behavior change. Part of that motivation may come from feeling that the materials are compelling.

In addition to the patient assessment, the HTN handouts were evaluated using an objective health educational material assessment format called the Suitability Assessment of Materials (SAM), as described in Chapter 3. The same 10 patients also rated a DVD about HTN.

Prior to my study, the clinic used four handouts to help patients understand HTN. I named them "high print," "bullet," "checklist," and "medical." To supplement these handouts, I did an Internet search for information on HTN and printed a five-page handout from the Health Literacy Now website (http://www.healthliteracynow.org/hypertension-or-high-blood-pressure.html). The website promotes using easy-to-read and culturally appropriate resources. The five-page handout ("HL Now") was longer than the ones from the clinic, but had more white space on each page and used simple, colored graphics.

At the clinic, 10 patients with HTN were asked to visually scan the five handouts and indicate which handout they preferred. As presented in the table below, the "HL Now" handout received the top SAM score of 90. The handout scores ranged from 50 to 90. Patients were asked to select the handout they preferred, and "HL Now" was the most popular choice.

Table B1.

Evaluation of Print Handouts on Hypertension

Handouts	**SAM Score**	**Patient Choice**
High Print	59	0
Bullet	71	1
Checklist	80	0
Medical	50	3
"HL Now"	90	4

Even though the "HL Now" handout was five pages long, the patients found it visually appealing because of the simple, colored graphics and the lack of dense print. The medical handout was the unexpected second choice—unexpected because of its low SAM score and complex, anatomical drawings that can be found in medical school textbooks. It also used higher-level vocabulary such as "aneurysm" and "hemorrhage" with no definitions or explanations of the words. No one chose the checklist even though it had a superior SAM rating, possibly because the illustrations of food choices were in black-and-white, not color.

Patty chose the "HL Now" handout because "It's colorful and has pictures." Sid chose two handouts. He liked the "medical" one because it showed how blood travels. He experienced a severe head injury in the past and related to the picture of the head on the medical handout. The "HL Now" handout was his first choice overall. When I showed

Francis the handouts, he took the time to read the "checklist." He chose the "HL Now" handout and asked for a copy.

Clara chose the "medical" handout because it showed how everything is related. Jack had no interest in the handouts and had no preference.

The clinic could print and distribute the "HL Now" handout because it is available online at no cost. Ideally, it could be reduced to two double-sided pages to save money and paper. One advantage of the handout is the colored pictures, which would be more expensive to reproduce. It is difficult to decide between cost and efficacy, and the handout might be too expensive to give to every patient. On the other hand, people who have reading challenges need easier-to-read handouts with larger font. The "HL Now" handout uses very clear language, lots of white space, and tells readers what to do about HTN in a very direct and simple way. Health education materials shouldn't replace provider instruction, but they may motivate patients to perform self-care at home. Patients should be offered a choice of printed handouts, as well as alternatives to print, for optimal patient education. Self-selection may make the information more interesting and relevant to the patient, resulting in better retention of the information and better adherence to the desired medical behaviors.

To understand more about patient preferences about video (DVD) media, I then conducted a short assessment of a video about HTN with 10 clinic patients. The DVD, described above, was a 12-minute-long animated medical cartoon about hypertension entitled "Learning and Understanding About Hypertension: The Silent Killer."

The same 10 patients who evaluated the hypertension handouts, described above, agreed to watch the video and then were asked what they had learned. In this busy,

overcrowded clinic, I set the video up in the large dining room away from the other patients waiting to be seen. The 10 patients were able to watch the DVD and hear the audio without too much interruption. Two of the 10 patients watched the video at the same time. Eight other patients watched it individually. I sat near them as they watched the video. The first five patients described below had been previously interviewed for this research study. Because all of the patients watched the video while waiting to see the doctor, the amount of discussion and verbal feedback was limited. Among the patients who had time to comment, no one stated that the video was inappropriate because it was a cartoon or that it was culturally inappropriate.

Patty learned that blood flows in two directions and that stress causes high blood pressure. Richard recommended the video to others and he learned what the terms "diastolic" and "systolic" meant. He knew he needed to quit smoking and that alcohol and salt can affect blood pressure: "You can improve your blood pressure." Don didn't have the opportunity to comment on the video because he was called to speak with the social worker. José thought the video was worthwhile. When he was offered the choice of watching the video with Spanish subtitles, he said that he doesn't read Spanish, only speaks it. We watched the video with Spanish audio because his cousin, who watched it with us, does not speak English. Trevor said, "The video tells you what you need to do—smoking, diet, exercise." He was interested in watching it again.

Jack, an Italian-American male in his 80s, rode his bicycle to the clinic. He was eligible for treatment at the VA hospital, but preferred to be seen at the clinic. He learned about veins and venous return and that "you can improve your blood pressure." Helen, an Asian-American female, has been seen at the clinic since December 2008 for

hypertension and was diagnosed seven years ago. She runs for exercise, checks her blood pressure at home, and stated that her blood pressure is elevated after running. She said that the video was OK and that she didn't learn much. "It would be good for a patient with newly diagnosed hypertension."

Clara, an African-American female, had long-term hypertension. Her mother had a "CVA" (stroke). She thought the video was worthwhile. "A lot of things go on that you need to know about." Sid, a Caucasian male, commented that the video showed how the heart, veins, and arteries are connected and said, "You can check yourself outside of the doctor's office." After watching half of the video, he asked how much longer it would take. It seemed as though he had difficulty sitting still for a period of time, but he did continue to watch the entire video. Francis, a 70-year-old African-American male, said that watching the video can lessen someone's fear about what's happening.

In summary, during this brief video assessment, it seemed that most of the patients became more familiar with medical terms and how their bodies functioned after watching the video and scanning the handouts. Overall, I learned that the patients approved of the video and thought that watching it was a worthwhile activity. Given that people learn in multiple ways and that redundancy is important, offering both a video and a choice of printed materials would seem to be ideal.

High Blood Pressure (Hypertension)

What is blood pressure?
Blood pressure is the force of blood against walls of the vessels that carry blood around your body. This is recorded as two numbers, the higher pressure is heard when the heart is actively beating (Systolic) and the lower pressure is when the heart is relaxing in between beats (Diastolic). If you are told your blood pressure is 120 over 80, this means your systolic pressure is 120 and your diastolic pressure is 80.

High blood pressure:
Normal blood pressure may increase and decrease throughout the day, but if your blood pressure remains elevated after several readings, it is important to see a doctor to help prevent and treat this condition.

140/90 = High blood pressure
* If you have Diabetes or Kidney disease it is recommended to keep blood pressures below 130/80
120/80 to 139/89 = Pre-hypertension (will likely become high in future, so it is important to try to prevent this with a healthy lifestyle)

Who gets high blood pressure: One in every four Americans has high blood pressure. Any individual, regardless of race, age, or gender is at risk. Once you have high blood pressure, it usually remains that way for your lifetime. That is why *prevention* and *control* of high blood pressure is so important.

What causes high blood pressure?
Most of the time, the cause is *unknown*. Sometimes it is due to narrowed arteries, a larger than normal volume of blood in the body, or a heart that is beating faster than it should. Other rare medical conditions can also cause high blood pressure.

Why do we care about high blood pressure?
Because it is dangerous and often without warning signs, most people who have very high blood pressure feel fine! But there are <u>many harmful effects of high blood pressure on the body</u>:

Brain: high pressure can cause a break in a weakened blood vessel that can bleed into the brain or a hardened, narrowed artery can be blocked by a blood clot, both resulting in a stroke.
Vision: small blood vessels in your eye may burst or bleed with high blood pressures; this can blur vision or even cause blindness if it is severe.
Arteries: high blood pressure causes arteries to harden, especially in the heart, brain, and kidneys, forcing the kidneys and heart to work harder to do their job.
Kidneys: are used to filter our body of waste products and remove them in urine. As the vessels in the kidney narrow and thicken, the kidneys cannot filter properly and waste builds up in the blood.
Heart: if the vessels brining oxygen to the heart narrow and thicken, the heart muscle will not get enough oxygen and chest pain (angina) will occur. If blood flow becomes blocked, a heart attack occurs. After working hard to pump blood against high blood pressures throughout the body, the heart is at risk of getting weak and will be unable to pump what the body needs (congestive heart failure).

* High blood pressure places you at risk for the 1st (heart disease) and 3rd (stroke) leading causes of death in America
Other risk factors for heart disease and stroke include: abnormal cholesterol, tobacco use, diabetes, overweight, physical inactivity (Age and Family history also increase risk, but are not within your control).

How to help prevent high blood pressure?
Lifestyle changes:

- Maintain a healthy weight: if you are overweight, even losing 10 lbs can help lower your blood pressure
- Increasing physical activity: even walking 30 minutes per day
- Healthy eating plan: increase fresh fruits and vegetables, lowfat dairy products, and avoid prepared foods with lots of salt.
- Decreasing alcohol consumption and quitting smoking can really help your blood pressure come down!

* If Lifestyle changes alone are not effective at lowering your blood pressure, it is important to see a doctor who can prescribe you medications that may help.

*National Heart Lung and Blood Institute (DHHS, NIH)

Blood Pressure

Low Sodium

Limit fatty foods

Maintain normal weight

Monitor Calories (portions)

You CAN Improve Your Blood Pressure

Name:

- ☐ Reduce salt intake
- ☐ Eat fresh or frozen Fruits
- ☐ Eat fresh or frozen Vegetables
- ☐ Drink/eat low fat dairy products
- ☐ Reduce fat and cholesterol intake
- ☐ Increase nuts/seeds/dried beans

- ☐ Olive and canola oils are better than other oils
- ☐ Whole grains are better than white flour

- ☐ Make smart protein choices
- ☐ fish/poultry/soy if possible

- ☐ Increase Potassium intake
- ☐ Potassium containing foods:
  - bananas
  - oranges
  - pears
  - prunes
  - cantaloupe
  - tomatoes
  - dried peas/beans
  - potatoes
  - avocadoes

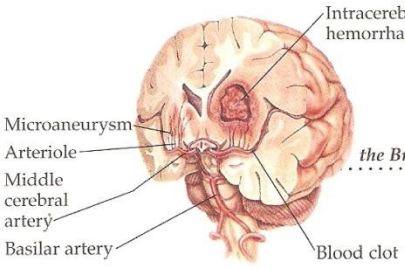
Quit smoking

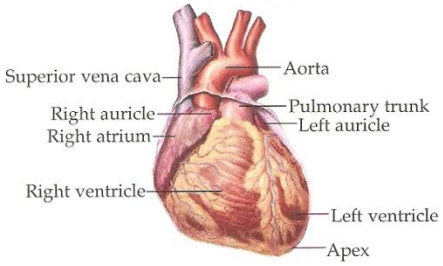
Limit Alcohol

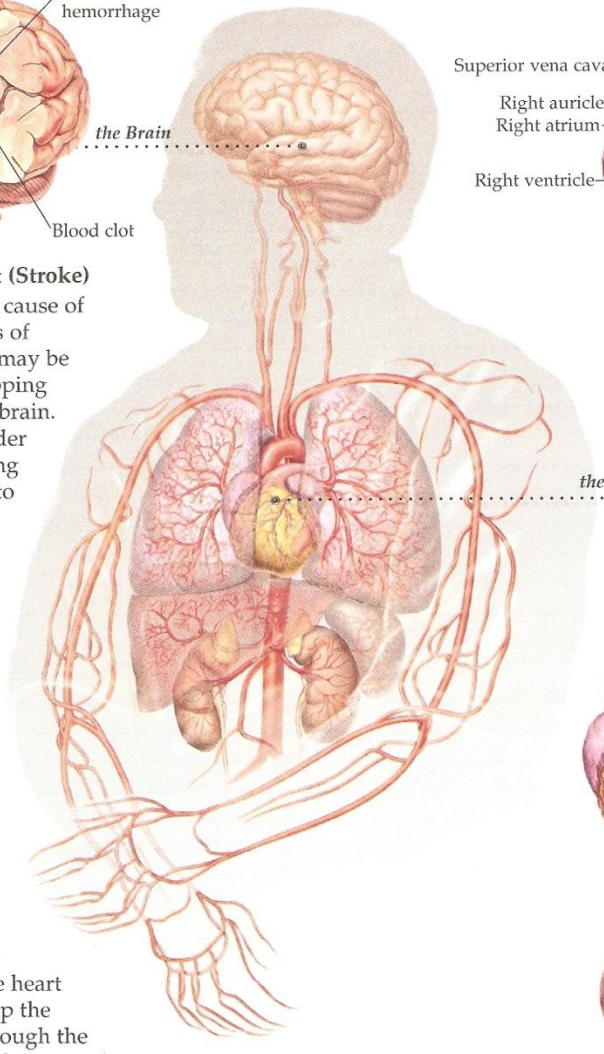
Drink no more than ____ drinks per day

1 serving : 12 oz. beer
5 oz. wine
1.5 oz. 80 proof liquor

UNDERSTANDING HYPERTENSION, LVH, & STROKE

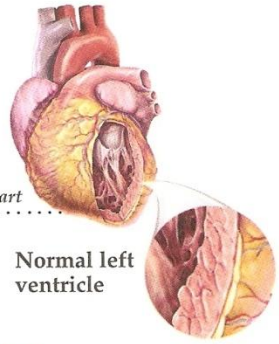




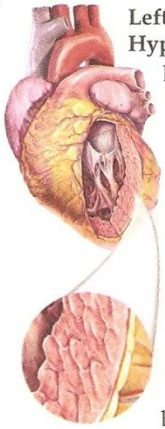


Cerebrovascular Accident (Stroke)

Hypertension is the major cause of stroke. The harmful effects of hypertension in the brain may be caused by blood clots stopping blood flow to parts of the brain. Aneurysms may burst under increasing pressure, causing hemorrhage and damage to brain tissue.



Normal left ventricle



Left Ventricular Hypertrophy (LVH)

Due to increased blood pressure, the left ventricle may become enlarged and thickened. This allows the heart to pump blood through the peripheral arterial system, compensating for the higher back pressure.

What Is Hypertension?

High blood pressure is hypertension. When your blood pressure is high, the heart must work harder to pump the same amount of blood through the arteries. The risk factor of hypertension (high blood pressure) can cause long-term damage to your heart, kidneys, and eyes. High blood pressure is defined as an average blood pressure greater than or equal to 140/90 mmHg (millimeters of mercury). The top number (140), systolic pressure, is the amount of pressure your heart generates when pumping blood out through your arteries. The bottom number (90), diastolic pressure, is the amount of pressure in the arteries when the heart is at rest between beats. Your blood pressure normally varies during the day. It rises during activity, and it decreases with rest.

High blood pressure is defined as

$$\frac{\text{Systolic mmHg}}{\text{Diastolic mmHg}} = \frac{140\ \text{mmHg}}{90\ \text{mmHg}}$$

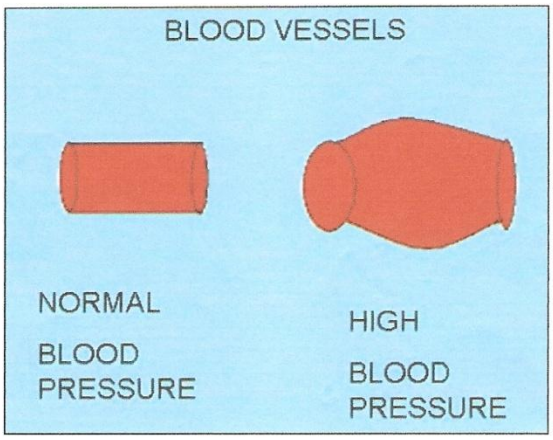
or higher

1. “High print”: The 8½ x11 handout was crowded with print that explained high blood pressure. I determined that it had an eighth-grade level of readability using the Fry readability formula (Doak, Doak, & Root, 1996, pp. 44–46.)
2. “Bullet”: The half-sheet handout concentrated on four dietary aspects of controlling blood pressure: low sodium, limit fatty foods, maintain normal weight, and monitor calories (portions). This handout was condensed from the “high print” handout by the clinic director and a student. It was clear and concise, but may be too limited in regard to the amount of information presented.
3. “Checklist”: The third handout had no identifying information about who developed it. It may have been developed by a student at the clinic. It was an 8½ x 11 checklist that focused on diet and also mentioned limiting smoking and alcohol consumption. The checklist was clear and direct and had some clip art as illustrations. Some instructions were vague. For example, “smart protein choices” were not defined or described.
4. “Medical”: The only color handout was supplied by the Merck company and was entitled “Understanding hypertension, LVH, & Stroke.” Half of this handout was print and half showed detailed anatomical drawings of the heart, brain and lungs.

Health Literacy Now

To know more, go to www.healthliteracynow.org

What is high Blood Pressure?



Hypertension is another word for high blood pressure.
Heart pumps blood to all parts of the body. The pipes or tubes that carry this blood are called blood vessels. High blood pressure is when blood moves through these pipes or blood vessels at a very high pressure.

What are the signs of Hypertension or high Blood Pressure?

High Blood Pressure does not cause any signs or symptoms. Most people do not know that they have high blood pressure. They find out when their doctor checks their blood pressure. Some people find out only when high blood pressure damages their body organs such as the heart.

How do I know that I have Hypertension or high Blood Pressure?

You must visit your doctor to check your blood pressure. If your blood pressure in normal then you check it again every 1 to 2 years. If it is high then you need to check it more often.

Why do people have high Blood Pressure?

There are many causes of high blood pressure. In most people no cause is found.
You have a high risk of high blood pressure if

*You eat a salty diet.

*Old age.
*A close relative with high blood pressure.

*Some medical problems such as kidney disease can also cause high blood pressure.

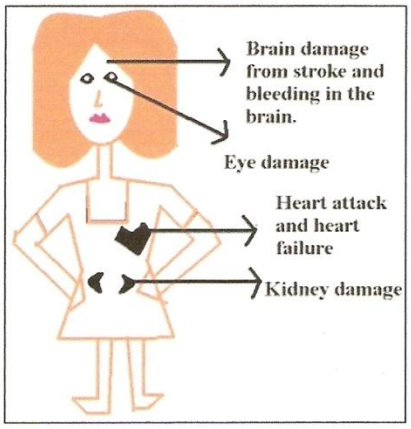
Do I need tests for Hypertension or high Blood Pressure?

Yes, your doctor will order some tests for you.

What are the long term risks of high Blood Pressure or Hypertension?

High blood pressure is very dangerous to health. It can cause

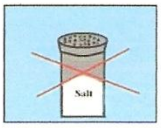
1. Brain Damage
2. Bleeding in the brain.
3. Eye Damage.
4. Heart Attacks.
5. Heart Failure.
6. Kidney Failure.
7. Death.



How can I lower my Blood Pressure?

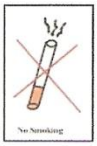
There are many simple ways to lower blood pressure

*Eat a diet low in salt.



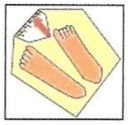
*Exercise daily.

*Stop smoking.



*Avoid alcohol.

*Reduce weight.



*Eat more fruits and vegetables.

*Try to relax.

*Take your pills for high blood pressure.

How do I lower salt in my diet?

* Cook without salt.

*Eat home cooked meals.

*Read the food label. If it says there is sodium in it then avoid it.

*Avoid cheese and buttermilk.

*Avoid salted nuts, chips, popcorn, pretzels, crackers and salty snacks.

*Avoid pickled vegetables and fruits.

*Eat fresh or frozen vegetables and fruits.

*Avoid instant soups and instant foods.

*Avoid canned vegetables, meats and fish.

*Avoid soy sauce, horse radish sauce, other prepared sauces and salad dressings.

*Avoid fast foods

*Avoid smoked, salted or cured meat, fish or poultry. Avoid bacon, ham and corned beef.

FIGURE 4-3
SAM scoring sheet

2 points for superior rating
1 point for adequate rating
0 points for not suitable rating
N/A if the factor does not apply to this material

FACTOR TO BE RATED	SCORE	COMMENTS
1. CONTENT		
(a) Purpose is evident	____	_____
(b) Content about behaviors	____	_____
(c) Scope is limited	____	_____
(d) Summary or review included	____	_____
2. LITERACY DEMAND		
(a) Reading grade level	____	_____
(b) Writing style, active voice	____	_____
(c) Vocabulary uses common words	____	_____
(d) Context is given first	____	_____
(e) Learning aids via "road signs"	____	_____
3. GRAPHICS		
(a) Cover graphic shows purpose	____	_____
(b) Type of graphics	____	_____
(c) Relevance of illustrations	____	_____
(d) List, tables, etc. explained	____	_____
(e) Captions used for graphics	____	_____
4. LAYOUT AND TYPOGRAPHY		
(a) Layout factors	____	_____
(b) Typography	____	_____
(c) Subheads ("chunking") used	____	_____
5. LEARNING STIMULATION, MOTIVATION		
(a) Interaction used	____	_____
(b) Behaviors are modeled and specific	____	_____
(c) Motivation—self-efficacy	____	_____
6. CULTURAL APPROPRIATENESS		
(a) Match in logic, language, experience	____	_____
(b) Cultural image and examples	____	_____

Total SAM score:_____
Total possible score:_____, Percent score:_____%

From Doak, Doak and Root, 1996

SAM Ratings of Handouts

1. The "high-print" handout rated a SAM score of 59 percent. It did not emphasize behaviors that result in lower blood pressure. There were no problems or questions presented for reader response and the eighth-grade readability level was too high.

2. The purpose of the "bullet" handout (what you can do to lower blood pressure) was not stated and there was no introductory context provided, resulting in a SAM score of 71 percent.

3. The "checklist" handout only lacked reader interaction. When a reader responds to print by solving problems, making choices, etc., chemical changes take place in the brain that enhance long-term memory. This handout rated a score of 80 percent.

4. Although the "medical" handout was multicolored, it was unsuitable because of high reading level and vocabulary, content about behaviors, and no reader interaction or summary was included. It was purely descriptive, not prescriptive. There were no patient instructions about what to do about HTN. A majority of adequate scores for other factors resulted in a score of 50 percent.

5. The "HL Now" handout received the highest score of 90 percent. It used a question and answer format that engaged the reader. It concluded with a list of 12 suggestions on how to lower salt intake, but did not review or summarize any previous information about high blood pressure.

Three handouts earned a superior SAM rating: the bullet, the checklist, and the "HL Now." The medical and the high-print handouts were adequate.

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